U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INTERAGENCY AUTISM COORDINATING COMMITTEE

SERVICES WORKSHOP:

BUILDING A SEAMLESS SYSTEM OF QUALITY SERVICES & SUPPORTS ACROSS THE LIFESPAN

MONDAY, NOVEMBER 8, 2010

The workshop convened in the Plaza Ballroom of the Hilton Washington D.C./Rockville Hotel and Executive Meeting Center, 1750 Rockville Pike, Rockville, Maryland, at 9:00 a.m., Ellen Blackwell and Lee Grossman, IACC Services Subcommittee Co Chairs, presiding.

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PRESENTERS (continued):

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Health and Human Services

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PROCEEDINGS

(9:10 a.m.)

Dr. Daniels: Good morning. I would like to welcome you all to the IACC Services Workshop: Building a Seamless System of Quality Services and Supports Across the Lifespan, sponsored by the IACC Services Subcommittee.

This is going to be a very exciting meeting. We have many state officials from across the country and disability experts who will be sharing with us about key issues related to services and supports for people with autism and other disabilities.

I would like to ask -- to welcome the phone listeners to this conference call and we have a webcast live. There were some technical difficulties earlier but if anyone on the conference call wasn't able to link into the webcast, you should be able to now.

And I would also like to remind you that after each of the speakers, it would be wonderful if questions from the subcommittee and committee members, if you could say your name for the purposes of the transcript so that people know who is speaking and for the conference call listeners.

But we are just really pleased and excited to welcome you all to this meeting. And I would like to now introduce our two co-chairs of the subcommittee and co-chairs of this meeting. Ms. Ellen Blackwell from the Centers for Medicare & Medicaid Services and Lee Grossman from the Autism Society. So thank you Ellen and Lee for all of your work on this meeting.

(Applause.)

Mr. Grossman: Good morning everyone. This is a truly exciting day. I want to welcome everybody here to this Services Subcommittee Interagency Autism Coordinating Committee Workshop. And for those of you who are listening on the web, I think that you will find that this is going to be a truly exciting day moving towards what we need to do in this country to help all individuals with autism.

The title of the conference is "Building a Seamless System of Quality Services and Supports Across the Lifespan" and that is exactly what we are beginning to build today. We are getting a dialogue going among people that have demonstrated that they are in fact moving towards moving these seamless quality services across the lifespan and we will be hearing from them today and building upon that. What our goal is, is to put together three to five recommendations for the Secretary of HHS, Secretary Sebelius. And our agenda is to have those recommendations available and presented to her hopefully right after the beginning of the year, which is quite an accomplishment but that is the goal of the IACC and of the Services Subcommittee.

In looking at this, there are a number of challenges that we have put forward to the speakers that are presenting today but one of which was not only talk about what you are doing today and how you have developed the services and the quality supports that you have but talk about where you want to be in the future. Talk about what the future of autism should look like in the next ten years.

At the Autism Society we have done a number of surveys. And just to summarize very briefly what we have been talking about at our organization and what we see the future, this is some of the comments that we have picked up, is that in the next ten years we have identification of autism by 12 months of age, if not earlier. We have interventions and treatments at the time of intervention that focus on the whole body and the whole life. We have every younger sibling of a person with autism in early intervention because we know that up to 50 percent of younger siblings will have some developmental issue.

We have comprehensive educational plans in preschool through high school that foster the greatest skill development. We have by the time that they graduate from these educational institutions an expectation by society that our people will have a job or they will get a degree. We have options available that ensure that everyone with autism will have the ability to be working and living independently.

When we have talked to parents, the parents talk to us about what their hopes and their aspirations are for their children with autism. And all that they want, in summary, is to be able to empower their children and provide for them in a manner that creates a better quality of life. And when we talk to individuals with autism, their requests are not that demanding. What they want, what they ask for, is to break the cycle of poverty, which we know most people with autism, the vast majority live the majority of their lives in poverty; that they can get a job because up to 70 or 80 percent of people with autism are unemployed; that they have housing options; and that society respects them and that society values them as individuals and for the great skills that they have to offer to society.

It is a lot that we have to move forward and I am confident that as we do, what we are doing today we are setting a model of open dialogue, working together across systems, across agencies, across different ideas, bringing them together in a comprehensive manner. And that is what we have to do as a community and as a society to forge and to strengthen the entire autism community and this conference today serves as the beginning for that dialogue and for creation of that new future that we are building.

So thank you all for your attention. Thank you for being here. And I turn the podium over to my great co-chair, Ellen Blackwell. Thank you all for your attention.

Ms. Blackwell: Okay. Thanks, Lee. I would like to particularly thank the speakers who are with us today because we have a wonderful group of folks that have come a long way and also extend a thanks to the people who are listening online who are not in the room with us.

I was thinking last night I just have a couple of things that I wanted to say and then I will introduce our first panel because I don't want to waste any time.

Services is an issue that I think crosses all autism advocacy. And it is a really important point that there are a lot different advocacy groups and each seems to have a core issue or two core issues but services is the one issue that I think everyone can get onboard with. So we are really glad that we have the Services Subcommittee and we look forward to continuing to work in this area.

The second thing I wanted to say is that in this country today, we are facing times of hardship; individuals, families, people with autism, states, communities. And in times of hardship, often great creativity and innovation emerges. So I am so glad we have people with us today who are creative innovators and who will be sharing what they have done in their communities.

So with that, let me introduce three wonderful people. Nancy Thaler, who is the director of the National Association of State Directors of Developmental Disabilities. Nancy has the job of being in charge of all the state developmental disability directors. Bill East who has the same job, except on the special education side. Thank you, Bill.

And lastly, Charlie Lakin. Charlie is a professor at the University of Minnesota. And much, much more, Charlie is an expert in services and he is going to tell us a lot about what is happening in the services system today and what we anticipate happening over the next ten years and also what that means for people with autism.

So thanks to all three of you. And with that, we will step down.

Ms. Thaler: Good morning,

everybody and to everybody who is on the phone. And thank you for that very kind introduction. I am not quite in charge of the 51 state directors, but I am responsible for supporting them and helping them anticipate the future and plan for it.

So let me go through my presentation, which is much of what I talk about when I go from state to state and meet with stakeholders in various states but this one's got a little twist on it because of the focus on autism.

Okay. So where have we come from? Humble beginnings. And the primary -- In the early 1970s, which dates my entry into the field, the primary service available for people with disabilities were institutions. Many states had fledgling community programs, community systems, often family support, but there is no doubt that the vast majority of the resources were in institutions.

In the early 1970s, the federal Medicaid program made institutional services an entitlement and made funding available for institutions, which helped in some ways to fix them up, remedy problems, and in some ways entrench them.

Mental retardation in the ‘70s was the predominant diagnosis applied across the board and for anyone who looked like they had significant disabilities and didn't speak. It was not a highly refined definition. And so you would go into institutions and find people who really had cerebral palsy, no cognitive impairment at all. But because they couldn't speak and there was no way to communicate, it was presumed that they had this diagnosis called mental retardation. The diagnosis was defined by what was then the American Association on Mental Deficiency and it was widely adopted in public policy. As people with the label demonstrated competencies, they would lose the MR label. So you heard a lot of families say I want the MR label because that is how we get services and they would make efforts to sort of hide the competencies.

In the '70s is when the families began advocating for school and some help at home. And we began to see more family support programs. Respite care was a big demand. And in some states, the families themselves, the early ARCs started day programs because not only did children not have the right to go to school but certainly in adulthood, the problem continued.

States began in this '70s and '80s to create some unit, often in the mental health office, that was devoted to mental retardation. So they were often not stand-alone offices but seen as part of mental health. And while the concept of developmental disabilities was introduced in the DD Act, it was not and has yet not been adopted by very may states, that is the comprehensive diagnosis of developmental disability.

In the '80s, we began to see changes when Medicaid was amended to allow states to use that institutional money in the community. And I would say that growth was exponential year after year, after year. We are going to see for the first time in '09 a net loss in resources in the national DD system but up until then, we have had growth every year. And the growth came first in response to closing institutions. This money became available just as all the litigation was heating up.

Operator: This is the operator. I would like to announce that today's conference is being recorded. You may begin.

Ms. Thrasher: Thank you.

And so states began to build community systems to get people out of institutions. And quickly the waiting list became a pressing issue because when you don't have admissions to institutions, people pile up at the door.

And even though mental retardation became less and less acceptable as a diagnostic label, not only because it is insulting but it is pretty useless, it doesn't tell you much about people, it became the basis for home and community based services because the basis for home and community based services is to create an alternative to the institution, which was called ICF/MR, which used mental retardation is the eligibility criteria. So we carried that definition out into community services.

So what has happened? A lot. Change to be proud of. We have seen a remarkable drop in institutional populations over the decades from 160,000 down to probably close to just 30,000 now. And this slide in particular is interesting to me because people talk about long-term care and our legislation passed and the Affordable Health Act has incentives to rebalance systems and move it to community. Well, that issue is really an elderly and other disability issues because the DD system has been moving out of institutions into the community for the last two decades and the balance is much more dramatically in favor of community in the DD systems, than it is in elderly and physically disabled systems. This was 2007. We need to update this with new data but we are probably now talking close to 70/30.

And how did we do it? We did it with Medicaid. What you see from 1990 through 2006 are the red bar graphs of the federal money. The bar graphs at the top are state funds. And what you see is every year less and less of the total dollars, a smaller and smaller percentage is state funding. States are using every state dollar they can to draw down federal money. So, it is a federal program.

We have about a million people in service and over half of them, of the people in service, close to 58 percent, are getting services while living with their family. This is often a surprise to people because they think the DD System, the mental retardation system in some states, although I think now no state has the words mental retardation in their title. I think the last state made that change. But people often think it is a residential system, group homes, but it is not. Most people are living with their families. And so we have seen an evolution of services over these years as the decades have gone from group homes and sheltered workshop and family support, then supported living, helping people live on their own. Employment is not enough but a big part of the service systems. And we talk about self- determination, consumer control. We don't do a whole lot of it but most states are doing some of that and self-advocacy. So we are always evolving new concepts in the service delivery system but people are waiting.

You can pick your number. Charlie Lakin does his best when he surveys the states to ask what the waiting lists are not and not everyone tells Charlie what they are. We have big states that don't report waiting lists. So 88,000 is a pretty modest number. The Kaiser Foundation estimates 280,000. We know it is a lot of people.

So what about people with autism? Well, I was a state director in the State of Pennsylvania for ten years. I worked there for 16 in a junior role or a senior role under the director and then I was the director for ten years. And I was the direct care worker in the early '70s and ran a community agency. So what I can tell you from experience is that we have been serving children and adults with autism for all those decades. We didn't always know it. That is the thing.

When I got into the field, children got -- almost no adults every had a diagnosis of autism. Children had the diagnosis but if they could smile, kiss, touch, or talk, they were considered autistic-like and as not really having autism. And it kind of didn't matter because the truth is, we didn't know what to do for people with autism, kids with autism.

So we were serving children and adults. And because anybody who had a significant disability kind of fell under the MR label, people would get in under the MR label. Adults were rarely diagnosed as autistic and generally got enrolled in the MR system. Sometimes children and adults were diagnosed as having mental illness and enrolled into the mental health system. And remember that because the DD MR systems were subsets of the mental health system, that was even more likely.

And I remember in the early 1970s, at least in the state of Pennsylvania, many of the state mental health hospitals had child psychiatric units. And I bet you if we could go back in time and see who was in those psychiatric, there were likely to be a lot of children with autism.

In the 1990s there was really, I would say, an explosion in the knowledge about what autism is and what can help. And I just have to say, and I think the medical community experienced this, parents with the tools of the internet, learned about these developments a lot faster than bureaucrats, professionals, or even the medical profession. So our states found themselves confronted with families expecting things that our members didn't even know existed.

And often what people needed or wanted was intensive and costly and there was no foundation for saying yes or no to something. Frequency, duration, types of service, they were really ill-equipped to manage this. And in the early, I would way, in the 2000s when I was still working in state government, it was an enormous controversy with families desperate to get intensive services early on and bureaucrats sort of paralyzed by the cost of it and having no basis to decide whether things were okay or not okay.

Certainly the growth in the number of children is unprecedented and continues to be. And the other factor is that states, there is no -- I can't say this but there are four states that sort of are entitlements now.

But the systems are not entitlement services. That is, they don't grow with the size of the population. All right? The typical Medicaid program, what the budget directors do in state government is they look at case load. What is the projection for caseload growth? And they budget that year-to-year. Well that is not true in the DD world. We have rarely been an entitlement. And the qualification is the state of Arizona is, to a great extent, an entitlement, Michigan, Wisconsin, and Vermont because of their reconfiguration under demonstration big waivers. Mike head is here from Michigan and maybe he will talk about that a little bit.

So, we have four states where services are an entitlement but that is pretty much it. and I believe Vermont is growing a waiting list, even though they are an entitlement.

Most states now have services for children with autism. Few states apply the definition of developmental disability for eligibility, the broad definition of DD. There continue to be conflicts over what types of services, frequency and duration. The needs of adults with autism who need life-long supports is becoming more prominent. The concept of early intervention and intensive treatment is widely accepted but we still don't have a lot of basis on determining which service, which treatment is most appropriate for which child and for how long and how much. Those are still questions left unanswered. So you see these blanket rules about up to $50,000 or 30 units of this to sort of contain costs, but often without a basis for knowing what is the most appropriate and effective.

The issue of children and adults with autism who have no intellectual disability at all is a real challenge for our states and certainly for families and individuals.

Okay, two things: demographics and economy. This is what I talk about in states all the time. The first is understanding our economic challenges. What we are looking at. Even before this economic crisis, even before this recession, we knew there was a problem. This is the fact, and you hear this all over the place, I think pictures tell -- replace a thousand words. Right?

Medicare, Medicaid, and Social Security are growing as the percentage of the total budget. So what I always say is in 1968 we all used to say, take the money out of defense. Yes, easy. Well that is not such an easy solution now. Defense, even though a big budget, is not the largest part of the federal budget. And this is the other picture, where it is going long-term. It is unsustainable. You hear this all the time. Here is the picture. Medicare, Medicaid, not so much Social Security, but Medicare and Medicaid are growing, growing, growing, because of the baby boomers but also because of growing healthcare costs. And so we have a trajectory that is unsustainable. We know this. You are hearing it. I hope all the people elected this past

Tuesday have the fortitude and the courage and the smarts to deal with this because the longer it is postponed, the bigger this problem becomes.

Okay, at the state level, the challenge now is the recession on top of that. The first problem with trajectory is not a today problem but it is pretty soon. But here is the today problem. Rampant unemployment, a recession. The red line is this recession. Okay, this recession is deeper, more severe, and will take a lot longer to climb out of than any recession I can remember in my adult life. And there were a couple of pretty bad ones. The oil embargo recession was pretty bad.

So what we have is when there is that kind of high unemployment, state revenues go down. We have unprecedented drops in state budgets. And what is the response? You read it in the newspapers. I am not going to go through all of these but states implementing cuts in core programs, healthcare programs, cutting rehab, cutting in-home services, cutting K through 12. Universities have taken a severe hit in this recession. Tuition is becoming unaffordable. So and we have had state and local governments lay off close to 300,000 people. If any corporation in this country announced that they were laying off 300,000 people, that would be a front-page story but it is eking out a little here and there. Okay, so that is the economy and so what I say to my members and their stakeholders is just, sometimes I use the Kubler-Ross cycle chart to say the quicker you can get to acceptance over denial and arguing and acceptance the better because we need to deal with this.

The other is demographics. This is the Census Bureau's picture of the Baby Boomers. So you can see in 20 years of that retirement age how many more people there are in that cohort than there were in 2000. And what does that mean? Well, it means that this is the ratio of people age 65 and over per 50 to 64. What is relevant about that? Well, it is 50 to 64 who are taking care of our moms and dads in their 70s and 80s. And the ratio of how many of us there are to those older folks is getting narrower and narrower, stressing the mid-level Baby Boomers in their obligations to provide care and it will continue to be more significant.

But here is the other slide with a different picture of this. The pink line going up, trending up, are individuals 65 and older between now and 2030 and it goes up. We know this. That is the Baby Boom group. The dark blue line going across is a line representing females age 25 to 44 working-aged females. They are the bulk of the direct care population for long-term care. So what does this picture tell you? Need goes up. Supply of direct care staff stays the same. Everybody who is going to work in 2030 is probably born. So we know who they are. This isn't just a guess. We know them.

So what does this say? This says

if we have all the money in the world to open up group homes for everybody, we can't find the bodies to staff them. Not only is it flat and it is not that everybody in that flat line is going to be working in long-term care, they are not going to work at all because they are taking care of mom and dad or they are getting little businesses like lawn mowing and grocery shopping to help people who have money to buy that.

So, demographic trends. In 1980, only 11 percent of -- this is not stability statistics, this is general population.

In 1980, only 11 percent of those 25 to 34-year-olds were living in multi-generational households back with mom and dad. In 2008, before the full effect of the recession, it increased to 32. In the city of Manhattan, it is 40 percent. And I bet if I asked people in this room to raise hands, how many of you are in multi-generational families have people, your kids lived home after college, hands would go up. We all know this phenomenon. It is true for people with disabilities as well. So here we have people with disabilities living with their families getting services between 2002 and 2008. We see a growth. We see a shift of where we are serving people. Why is that? It is a no-brainer. Costs in an institution are huge, even in a small group home, but as soon as you get into the Medicaid waiver or supportive living services, any service that does not use 24-hour staffing is far less costly than any other model that uses 24-hour. So the trick here is to stay out of as much as we can, 24-hour staffing arrangements so that we can spread resources. And here are all the slides together. On sustainable trajectory financially, on unsustainable trajectory demographically, the fact that we have waiting lists and demand and so we have got what is the solution. Well the solution is, acknowledge the paradigm is shifting. We don't have to shift the paradigm. It is shifting. And it is more people are going to be living with their families longer than maybe anybody had planned.

And so in this paradigm, remember that we are a paradigm that is based in residential services. I grew up in institutions. Most of the leaders in the field that are Baby Boomers have their roots in institutions and then group homes. So our paradigm is residential services. Our paradigm is you know, when something goes wrong, you fire somebody. Right? You move the group home.

We don't really have necessarily a paradigm for supporting families. So a little bit about this. When I say families, I think very broadly. Parents, siblings, grandparents. There is a wonderful sibling movement going on in this country growing. Families are very complicated. Group homes are very simple: hire people, fire people, report them for abuse, investigate. Families are very complicated. They help each other, they sacrifice for each other, they hurt each other, they apologize, they forgive, they have fun. They have routines and customs that are unique to them. They have secrets that they don't talk about. They have troubles. They get tired. They get discouraged. They do impossible things. They do commit abuse and take advantage of family members. They are resourceful but they can't do everything alone. All of those things are true and they are very complex.

Families are the primary support. They are resourceful but they need support. And the family is the context for everything. Personal outcomes depend on the family and what I mean by that is if you have somebody in a group home now or an institution but not many people and you sit down and have the individual plan, it is all about me. It is all about the individual.

That plan only talks about what I need and what people are going to do for me. It doesn't talk about my obligations. It doesn't talk about how I am going to sacrifice for other family members or what I am going to contribute. We don't know how to do that.

But in families, it can't be just about you. Families are dynamic and interdependent. And so we all make sacrifices. Sometimes you don't go to the movies on Friday night because Dad has got to work late. And so how do you write an individual plan that recognizes all of that?

So our challenge here is and the principles we want to make sure is that even though adults may be living with their families longer, keep the self in self-determination. Remember, it is about the person actualizing their life even as we account for what the family needs. You can't get there without being person-centered and using person- centered planning and practices.

We need to think about self-advocates and their families having more control over funding and services because after all they are the core service. And we need to assume employment because the path to inclusion and self-determination is a job.

So we need to think about providing a full array of services to people in their family's home. This is more than respite care. Families need some direct services coming to their home but they still need stuff in the milieu that they can draw on without being a billable unit.

So things like a 24-hour or at least an 18-hour help line. Consciously building a parent-to-parent network and a self-advocacy network so people can draw on each other's strengths and be self-reliant.

We need to think about health when people are living with their families because our outcome data tells us that people who are living with their families go to the dentist less, go to the GYN less, go to the doctor's less, see their friends less, by the way. So while generally they are happier and safer, there are aspects to living with your family, which will be true for all of us if you went home to live with Mom and Dad, that we need to consciously partner with families about.

Innovations. Certainly individual budgets. Giving the provider the contract with money makes less and less sense when people are living with their families. And what I mean by that in the DD world, the traditional model is big agencies get big budgets and then the family gets to pick which of the two agencies they go with. That makes less sense when the families are the core foundation. There should be a lot of flexibility in a budget that they can pick and choose providers and the types of services that they need. Hiring relatives is a new paradigm. States are already doing this. A very good idea. Cautions about it but it is one solution to the support challenge that we have.

And things like using evidence-based practices, one of the biggest challenges and the reasons families ask for out-of-home care is behavior challenges in the home. And what we know is behavior is typically related to some mental health issue, even if it is only depression or post-traumatic stress from having been made fun of a good part of your life and being left out and that if we can do good mental health treatment along with behavior support, we can help people manage and have a really good life.

We do need solutions for people who don't have families. And so when I say families, Mom and Dad, sisters, brothers, extended family whom we have often seen willing to do ongoing support if they could count on the service system. But there will be people who do need something 24-hour and one of the models that the states are developing is something called shared living. I won't call it foster care because it is not about three hots and a cot. It is about finding people in the community with a home who are open to sharing that home long-term and matching people up and supporting them to do that.

So in closing, what I say to the states is the questions are not whether people who are old or disabled will be living with and relying on their family members for support but whether people and their families will struggle alone or have a great life because the supports are there for them and they are part of the community.

And I say this because I am not proselytizing that people should live with their families or have to live with their families. What I am saying is like in the typical population, it is just happening because we can't afford out-of-home services. So let's look that in the face and be conscious and planful about it. And we will know that the services are good enough when if we have an out-of-home placement available, they say never mind. This is working really well for us.

And my last slide is: What do people really want? Family, friends, a job, a little fun, and I say self-advocacy because for folks with developmental disability, self-determination and making your mark on the world is a bigger challenge than if you don't have a development disability. And so self-advocacy is not a luxury. It is essential, I think.

That's it. Thank you.

(Applause.)

Dr. East: Well, good morning. I am Bill East, Executive Director of the National Association of State Directors of Special Education and I am very pleased to be with you and to share my views. Nancy, thank you so much for your great presentation. I am going to talk a little bit about the economy, too, but not so much as you did as I go through my slides this morning.

In the interest of time, I am going to get right with it. Here are some items that I want to talk about. First of all, my view from today, 2010, and I want to focus on six areas that I hear discussed quite a bit in the educational communities out in school districts and schools. The impact of the economy and I put that right up front because we have to -- we don't need to dodge that; the research versus practice discussion that I hear a lot; the causes of autism debate; autism separate or part of special education discussion. A real big issue for people in the public schools is the service provider preparation. Teachers and related services personnel, how do we prepare them to do the job we know they need to do. And then the sixth one is the impact of technology on our work. And then I will end with just a few comments about my view of the vision for 2020.

All right. My view of today. Have you ever been asked to speak and you get there and you look around the audience and you realize that you probably know less about the topic than anybody in the room? That is kind of how I feel as I stand before you because you are the specialists. I am going to share some thoughts from the public schools and the people that work there and see what you think about it.

First I want to talk a little bit about the impact of the economy. I could just say it is bad and sort of refer to Nancy's comments and let it go at that but what impact is it having in schools, on our own schools?

Well, services sometimes suffer. The teacher/people ratio seems to be going up. The availability of related services seems to be diminishing. Funds for things like transportation and other needed related services are diminishing. That is what I am hearing.

But what is reality? The IDEA or the Individual with Disabilities Education Act is an entitlement. So it is not subject to economic ups and downs. It is not limited by the numbers of students on the spectrum. If a child has a disability label and because of that label they need specially designed services to get it. So that is what our schools are facing.

I want to talk just a moment about

research and practice. And here is what I want to share with you. Don't let the pursuit of perfection get in the way of the good.

I want to tell you a little story about research and practice because I believe that research should inform practice, and practice should inform research, and we should all be working together for the good of the people we are trying to serve.

I remember back in 2003 we knew there was going to be some language in the reauthorization of the IDEA around response to interventions. Have you heard that term RTI response to intervention? And so I went to my colleagues on the Hill working in the Department of Education and says we need to work together to inform all these people out in the schools that are going to be dealing with his. And so the response I got was no, you don't, and we don't. We need to wait for the research to tell us what to do.

And so my response to that was, well, that is good but when school starts this fall, kids are going to come to school, people are going to have the responsibility to deal with RTI, response to intervention, and we need to do something to help.

And so what I did was to get some colleagues that were practitioners to write a book on response to intervention. And to date, we have either disseminated or sold some 68,000 copies. I think there was some interest in response to intervention. And so my advice to all of us who are interested in autism, there is a lot of good that we know. There is a lot of good research out there. There is a lot of good practices out there. If you go to the website, a tremendous amount of information. Let's use it. Let's don't wait. We can't wait around because the buses run, the bell rings, the teacher has the students in her classroom and she needs to know what to do.

So here is some advice I have for researchers. Give us your best but in a format we can understand and use. One of the things we are trying to do at NASDSE is take research documents that sometimes are 50, 60 or more pages in length and analyze those and provide school teachers and administrators say a two or three-page document that synthesizes what is in the research and helps them determine what to do next.

Another piece of advice is do research in real-life situations. So much of the research that I have seen many times in special education are done in college lab situations. That is not where the action is occurring. It is occurring out in schools, in classrooms with teachers. And give due weight to parent and service provider experience.

I have always recognized through years of experience that usually the greatest expertise is closest to the child; and that is the parent and the people that are teaching and working with the child every day and so we don't need to forget that.

My advice to service providers is to give us your best but use the research-based and evidence-based information that is available to you.

Now as I talk with and travel across this country and look at what is going on in schools and I look at autism, there is a lot of research and evidence-based practices available to our teachers and our administrators but they are not using it to the degree that they should. And so, we need your help advising them to do a better job in doing this.

And a second piece of advice to service providers is to give implementation fidelity a chance before changing. I see people trying something and well, it didn't work. You know, we tried it a week and it didn't work. If you are going to give the fidelity a chance over time to make sure it whether it works or not. So I see teachers and service providers constantly changing, trying to figure out what works. Give it enough time and then if it doesn't work, then go to something else.

And again, give parent experiences due weight. I see parents coming in offering up help. As Nancy said, the history, as I see it 10 to 15 years ago, parents are way ahead of the school, teachers, and other personnel in information, knowledge, expertise about autism. And so school providers need to give due weight to those experiences and knowledge that parents do have.

Now, I put together just a short list of what service providers need. And this is just from my experiences of visiting schools and talking with people that are running the schools doing this work.

Parental participation in implementation is needed. As a matter of fact, it is essential. Preparation and ongoing support is needed. A lot of times we get the preparation through various means but we don't get the ongoing support that helps the teacher on a day-to-day basis provide the services they need.

A community of practice with

involved stakeholders is needed. I am going to talk a little bit more about communities of practices and the value of using all the stakeholders involved in autism to get the job done. I will talk a little bit more about that in a minute and what we are doing at NASDSE to try to promote that.

Peer interaction, support, and coaching is needed for our people out in the schools. Quite often, a teacher will be faced with a situation like this. They will be in a small school or a small community. They have one or two students in the whole school that is on the spectrum and they are the only teacher that is dealing with that student. They have no peer interaction and sometimes little support and no coaching to help them get through the day. So that is needed tremendously. Technology helps us quite a bit on that because they can go online and if there is some E-mentoring program somewhere, they can take advantage of it but we still have a long way to go.

They need research in usable formats, as I mentioned a few moments ago. Just what does this mean? Just tell me what do I need to do and how do I need to do it.

Service providers need lifespan view or a lifespan focus. Quite often we get in our little narrow focus and we worry about the students with autism that come to us in our time from K to 12 or birth to 16 or birth to 20. It is so important that we know what is going on before we get that child and what are the opportunities after that child leaves us, so we can do the job in our time with them that will be productive and will prepare that student and their family for the next level.

Responsible realistic policy is needed. Since my organization works quite a bit in the policy arena, I see a lot happening from time to time about policy and some of it is realistic and responsible and some of it is not. My way of thinking, if the policy is too far behind or too far ahead of the practice, then you have a mismatch. So you really have to look at what is the capacity of the people that are going to be doing the work to react and to implement this policy, whatever it may be and then move the policy along in incremental steps, as we bring practice and research along.

And service providers need paperwork focused on implementation and services, not so much on providing numbers for Washington. And that is kind of a sore spot with some of our school people, because they tell me they spend a lot of time filling in the boxes on this piece of data or that piece of data, which is quite useful at the local level. They question the overall use at the federal level. But they really need, when they are doing paperwork, it really needs to be focused on progress monitoring and those kind of things that is going to move the child from here today to where they need to be tomorrow.

And as was mentioned before, service providers need to the adequate resources in order to get the job done.

And my last point there that I hear quite often is program fidelity with flexibility. So what do I mean by that? Service providers need to pay a lot of attention to program fidelity; doing the right thing at the right time with the right people and giving enough time to make sure it works. But they also need flexibility and those times when they need to adapt to those changing resources, the economy, and changes in policy and social worth.

I hesitated to get into this. I did a presentation a couple of years ago and Lee Grossman was there out in Kansas and so as part of that preparation for that presentation, I had the staff looking for the causes of autism. So I filled up several slides, as you remember, Lee, with the causes of autism and I thought I had done a pretty good job, only to realize that that was only a small part of the list. And so after that, I went out and I started talking with school people about what difference does it matter. If you have a child on the spectrum and they show up at your door, what really difference does it matter? And so what they told me, it doesn't matter very much. It has very little relevance of what happens in schools. They say we have a child in our school on the spectrum. He or she must progress toward expected outcomes which are clearly defined now in schools about what is expected. And they need to know what knowledge, training, and support do we need to help this child and family. And so the causes is not something that I hear at all when I visit schools.

Now, as you look those second two bullet points, you see there, well maybe he's in a dream world. There are so many problems out there and the experience I have and when I took my child to school is not so positive.

But I can tell you after watching services in schools over the last 20 years and, in particular, in the last ten, I am seeing a major change in the attitude that families face when they go to schools. From a time in the past when parents showed up and said I have a child on the spectrum and the response was, oh no, what do I do to now, okay, let's see what we can do together to make services happen and outcomes happen. It has not occurred in every situation but I am seeing a change.

You know, I hear this discussed quite a bit and not just with autism but with other disabilities as well. Do we need to separate or do we need to be part of special education? Does being part of special education dilute the impact we can have? Can being separate increase the impact that we have?

Just a couple, just a few years ago when the last reauthorization of the Higher Education Act passed, there was an initiative that was put in there that provided accessibility and funding for students with intellectual disabilities to attend college. Are you familiar with that? And now there are colleges around the country now that are developing programs so students with intellectual disabilities can experience the college life. The question still remains, you know, what is going to happen in the end when they may not graduate. Are they going to get a certificate or whatever? That is still to be decided at the individual institutions.

But as I looked at that initiative and I say you know, that is good. These people are going to have that experience. But then I thought, well if it is good for this population of students, why isn't good for students on the spectrum? Why isn't it good for other kids with disabilities so all kids can experience college life? And so picking out this one disability may be a good thing for the kids that are in that disability but what about everybody else? So it is something to think about.

Separate funding by state legislatures for autism is good and that seems to be a trend. But I wonder, you know, while that is good in the sort haul, what is it going to mean long- haul when the disability community needs to work together to make major changes across the board in not only funding but policy and whatever. It is something to think about and something for your committee to discuss.

I want to talk now because I believe we are better together. If we are going to provide the solutions we need and the programs we need to ensure the outcomes we want for our kids, we need to do it together and we can't do it separately.

So I want to talk to you a little bit about some of the work that my organization, NASDSE is doing to try to promote this concept of we are better together and working together.

We have a project at NASDSE called the IDEA Partnership. And in that partnership, we have a National Autism Community of Practice that I will talk about in a few moments. We also have a center, the

Personnel Improvement Center, that works on recruitment and retention, and the E-mentoring and other things around supplying sufficient numbers of teachers and related service personnel. I want to mention a little bit of work that they are doing. And then we have a government relations staff which actually is real small, two people, that look after our interest with national disability issues. They participate in education coalitions focused on policy and appropriations and I will mention a little bit about that.

All right. The IDEA Partnership supports autism with a National Community of Practice. I don't know if you know about this but a community practice is a group of stakeholders. It is all the stakeholders that are interested in a particular topic, interest area, in this case autism. We already have 16 states that are working in that community. There are 11 practice groups. A practice group is an issue-based interest group in autism. It could be around causes. It could be around services. It could be around related services. It could be around transportation. Any of the issues. But the fact remains that we have this work going on. State teams meet to plan work. Partners write dialogue guides. And that is taking all the information, research that is available and developing a guide around the dialogue that people need to be talking about around that topic. In this case, autism.

They have developed or are developing resource collections which are dialogue guides and websites and other information. We developed a resource collection back in march and launched our website on that. And in April we had 19,000 downloads. And so what that tells me, there is a lot of people out there that are searching for information around autism.

Something that they should know about that is evolving is www.learningport.us was launched last year and now has well over 800 entries of researched or evidence-based programs or modules for teacher use. So it is a tremendous resource that we are having for people at the local level around a number of topics. And the collection includes resources for ASD. For example, the OCALI materials, the modules that you are familiar with are there. That is just one entry out of the 800 plus and you know that entry has quite a number of modules.

I don't know why I put LearningPort twice on the slides. I was either sleepy or I made a mistake. So, you pick.

Participant: It's just that good.

Dr. East: Maybe it is that good. I don't know.

And then I want to refer you to a website, the IDEApartnership.org. You can go there and then from that website, there is a tremendous amount of information about all the issues about our communities of practice. Autism is not the only one. We have communities around transition, RTI, mental health in schools, and so forth.

Our Personnel Improvement Center, I wanted to mention that because this Center helps states with recruitment and retention of teachers and related service personnel. The next thing is something I really want to point out. On that website is a database of preparation programs. And so you and I can watch the evolution of programs that are being developed across the country in colleges around autism. And that is important because they are growing but they are not near as many as we need.

Also on that website, you will see information about E-mentoring. That is helping teachers that are newly hired out in the field to have a mentor when there is no one available there onsite to do it. And that model we are trying to grow and have great implications for people that are working with kids on the spectrum. So there is the website for that. It is personnelcenter.org and I encourage you to go there.

And our government relations work

and our policy work, we work through coalitions looking at bills and suggesting language for bills and supporting appropriations bills that will benefit all of us. And we do have someone that participates just with attendance at the coordinating committee meetings and you have those.

I want to speak just a minute about service provider preparation, which is a huge issue for people out in the schools, you know, and the question is what is appropriate preparation. Does it have to be college preparation with a license or some organization preparing people with a license or certificate or some experience-based preparation with a certificate or some vendor- based preparation with certificates or something else. What I am seeing is a combination of training and preparation across the country.

So what is best? We need the researchers to tell us. We need your experience to tell us so schools and states can make informed decisions about how to go about preparing people that are going to work with people on the spectrum.

How am I doing on time? Bad, I'm sure. I need to move it.

I want to mention just real quickly the impact of technology because that has been huge and you know that. I just want to mention three things that are considered high- tech because things like Facebook, Twitter, email is not even on the list, these things are now considered low-tech. Operating in the Cloud is considered low-tech. What is high- tech? Some of the new things that you have been seeing on TV and other places, Robotics is one. If you saw the NBC series that they did, you saw Bandit the Robot. He was working intensively with individuals on the spectrum with huge success. That has great promise.

We now have the availability of bio-sensors, research going on at Vanderbilt that will detect how a child is feeling. So, they can detect anger and joy and all these kind of things that sometimes students on the spectrum don't show us.

I was real intrigued by an annual conference that we had just a couple of weeks ago with a presentation on Avatars used in virtual teacher preparation, where a close frame of kids, the Avatars, were made available and a teacher, a new teacher, or a prospective teacher, and go in that environment and work on situations that are behavioral situations and learn how to handle a situation virtually and not have to make those major mistakes in the classroom with a kid. Great promise. And that program is going to be expanding. So that is some of the high-tech stuff you are going to see.

All right, because of time I have got to just end with a couple of slides. So a vision for 2020. And here is the first one. all people with ASD will have the services and supports they need and desire throughout their lifespan, helping them reach their fullest potential. You recognize that, don't you? Because that is yours and that is mine, too and should be for everybody who is out working in schools.

All stakeholders helping people on the spectrum will be prepared and supported. We are making strides. We have got a long way to go. Hopefully, over the next ten years, we will be much better.

ASD stakeholders will participate in a national, state, or local Community of Practice. I wish I had time but it takes about a half a day to really get into what Communities of Practice are and how they operate. I hope you will go on our website and learn more about those but we are better together. And when all stakeholders are working toward a common goal, we are much better.

Major advances will be made in understanding the causes of autism, which will service all. Advances in technology will enable communication beyond our current expectations. We don't even -- We can't even imagine what we are going to see three and five years down the way, much less ten and twenty.

Schools will be learning hubs available to all. I really see that happening where kids are not going to get all their education in the schools in the future. They are not doing it now. They are getting a lot virtually. They are getting it in the communities. They are getting it in other places and also getting it in schools. So, that is going to be a major change in the future.

The numbers or percentages of people with ASD will have decreased significantly. I don't know if that is a wish or that is what I see for 2020. But I think the research and the technology is going to make so much of a difference that we are going to see things change quickly. And people with ASD will be everywhere in society but we won't notice.

Thank you.

(Applause.)

Dr. Lakin: Thank you. Well, Nancy sort of told the story I was planning to tell. So, I am going to go over a bit of what she said, perhaps skipping enough that we will get closer to schedule. But I think I will start in a little bit of a different place.

You know, what we need to do in the next ten years is to keep the promises we made to people with developmental disabilities in the past ten years. And those promises are found all over the place. They are found in the Developmental Disabilities Assistance and Bill of Rights Act. They are found in the Americans with Disabilities Act and in the Supreme Court's affirmation of that in the Olmstead decision. They are found in IDEA. They are found in the Rehabilitation Act. They are found in the U.N. Convention, which our president has signed. They are found in Medicaid law and regulations and in all sorts of places.

And there is some important national goals in those promises and I am borrowing here from a document that Ari and some self-advocates put together with the support of the Commissioner on the Administration on Developmental Disabilities, which tried to sort of summarize the national goals that have been held out for people with developmental disabilities. And they are fairly important and quite ambitious. People have been promised increased self-determination and personal control over their lives. They have been promised opportunities to live and participate in their communities. They have been promised opportunities to improve their quality of life, as they themselves define it.

Families have been promised the support they need to care for and protect their family members. We have said we are going to invest in individuals' potential to live productive lives in the community and we have assured people access to high quality health and social supports.

And we have made these promises and the challenge for the next ten years, in my mind, is simply to keep them.

In terms of residential services, that is, people living outside of family, we have made really great success in ways that are consistent with those promises. Since 1976, we have gone from about 53 percent of people receiving residential services living in places with six or fewer people to about 73 percent in the U.S. in 2009. We have increased the total number of people receiving residential supports outside of family over that period by about one-third. So, progress is happening.

We have also found, using the national core indicators, which is a program that Nancy's founded that people are finding fairly good lives in the services that are being provided to them. This just shows the percent of people responding positively to a survey about how they feel about their services. You know, about 80 percent and they are all kind of expressed in the positive dimension. So about 80 percent say they are not afraid at home, not afraid in their neighborhood, they generally feel happy about their lives. About 90 percent like their staff, like their home, like their staff where they go during the day, like what they do during the day but about 54 percent say they seldom or rarely feel lonely.

And we have learned that housing size is greatly associated with that outcome. People living in places with one or two people with disabilities are much less likely to feel lonely than people living in larger places and particularly less lonely than people living in places of seven or more. And people living in the smaller places are also much more likely to like where they live. And that makes me particularly happy that you are focusing on housing today because the driving factor in those outcomes is really people living in homes of their own.

There is no predictor that we have in our whole arsenal of independent variables that is predictive of people's sense of well-being than whether they are living in a place that they own or rent in their own name.

As Nancy said, we have moved rapidly toward people living with family members. We have gone from 48 percent of people living with family members to 57 percent in just the past decade. And this is true in the Medicaid waiver services program, too. Back in 2003, about 42 percent of Medicaid waiver recipients lived with family members. Today, it is up to 48 percent. Two-thirds of the people who have come on to the Medicaid waiver program in the last decade are people living with family members. Quite a contrast with the decade before that.

And what have we found about people living within their own homes, living with family members? We have found they feel less lonely. They feel less fear in their home. They are more likely to feel happy about their life. They are more likely to like where they live.

Now it is really important to acknowledge that these central tendencies have nothing to do with individual lives. It gives us some sense of comfort that perhaps this is not a trend that is negative in large measure but really, we don't know enough how individuals feel. We certainly don't know enough about how families are affected by this trend and we need to recognize that increasingly, this is not a choice families are making. This is an expectation of families. And the reason for that is quite clear. As shown here, people living with their own families in four states in which we did some research. It cost about $25,000 a year to Medicaid programs. People living in staffed residence in the community cost about $70,000 a year. And people in the ICF/MR programs cost about $128,000 a year. So why this is happening is fairly clear in economic terms.

Well, this busy slide is just kind of a growth in the Medicaid programs for people with developmental disabilities. Today there are about 650,000 people receiving Medicaid ICF/MR and waiver services across the United States. You can see in the red line the rapid reduction in the number of people who are in the ICF/MR programs from about 150,000 to down to about 90,000 since 1992 and the very rapid growth in the number of people receiving Medicaid waiver services.

Today, about 86 percent of the people who receive either Medicaid waiver services or ICF/MR services are in the waiver programs. As Nancy said, at CMS they talk a lot about balancing. Well, we are way beyond balanced and we are also growing. The bottom line is the total long-term care expenditures for people with developmental disabilities. They have gone from about ten and a half billion dollars in 1992 to about 37.3 billion dollars in 2009. That is a rate that is slightly faster than Medicaid in general and quite a bit faster than Medicaid long-term care services in general.

Let me just show you a very busy chart that shows where people with autism are serviced within the Developmental Disability Services. On the left-hand column are the states in which autism is treated as a related condition within the state Developmental Disabilities Services. In other words, it is included within the general service package for people with developmental disabilities. And in the other two columns, the one for children and adults, are states in which there are specific Medicaid waiver programs for people with autism.

As you can see, the system is really dominated by the inclusion of people with autism into the general Medicaid waiver for people with the developmental disabilities. There are a few states we don't have data from yet and there are a few states like Connecticut that have a special program but it is not in the Medicaid service program.

So that is just kind of a quick view of where that stands.

This slide just shows the distribution of autism and intellectual disabilities and other disabilities that sort of feed the adult developmental disabilities programs in the state. And you can see in the dark blue the rapid increase in the number of people with autism and the decrease in the number of people identified with intellectual disabilities in those service systems. And let's see where those guys end up.

Well, this is data from the National Core Indicators from 25 states and it shows the percentage of each age cohort in the adult Development Disability Services made up of people with autism. So you can see in the youngest age cohort, 18 to 26 in this analysis, people with autism make up 16.5 percent of the total service recipients. You can see how dramatically that drops over the years. So this is sort of that front wave of people that we saw in the previous slide.

And sort of consistent with other data on autism, this shows the percent of people identified with autism who are male and female, the blue being the male. You can see about 70 percent in all age cohorts of the people identified with autism are male, much higher than the people without autism on the right-hand side of the chart, about 55 percent.

The other thing that is sort of interesting in the distribution of people with autism in the adult service system is sort of the bimodal distribution. You can see among people without intellectual disabilities in the Developmental Disability Services, there is a much, much higher prevalence of autism. And then autism is also higher than average among people with severe and profound intellectual disabilities.

So we kind of have two groups of people identified with autism. People who have autism and are affected in ways that lead to severe and profound intellectual disabilities or at least scores on assessments that are in that category and then a growing number of people who don't have intellectual disabilities but who are served in the developmental disabilities systems.

And this again, blue is people without autism; red people with autism. People with autism -- no. I got that turned around. Blue is autism. Red is not autism. People with -- no. That is right. Excuse me. Okay, I got it. Okay.

People with autism are more likely to live in their family home in the Adult Service System. They are less likely to have a home of their own in the Adult Service System. Now that may in some ways be associated with that trend that I showed where these tend to be somewhat younger people.

Just with regard to a diagnosis of people with autism in the adult system less often have a psychiatric diagnosis. They are less likely to have a vision impairment. They are less likely to have a physical impairment.

They are considerably less likely to have Down Syndrome. Except for Down Syndrome, these might be associated with age again.

I want to look just quickly toward the future. These charts are in your packets.

Well, as we look toward the future, as Nancy said, we really are in a time of real competition for resources within an aging society. And by resources, it is not just the amount of financial resources, it is the challenge of resources to provide care. It is the number of people who want and need resources and it is the unprecedented growth in the number of people needing long-term care services.

And so as we come out of this recession, I think we can sort of turn to our two philosopher princes to look for a perspective on what faces us. Dan Quayle thinking the future will be better tomorrow and Yogi Berra thinking the future ain't what it used to be. I think maybe Yogi has the perspective.

Forgive me for this. I did a white bar on a white sheet and so it sort of disappears. It is there. You just can't see it.

(Laughter.)

Dr. Lakin: This just shows between 2010 and 2020 and then between 2020 and 2030 what is going to happen with our national population as it reflects as it relates to long-term care. And Nancy sort of covered this but our population between 2010 to 2020 is going to increase by about nine percent. If the standard association of disability with age and the long-term service use for people 65 remains at the rate it is now, our population will increase by nine percent. People with disabilities will increase by 15 percent and the people using long-term services and supports who are over 65 will increase by 20 percent in the next decade. And then in the decade after that, our population increase will be six percent. The number of people with disabilities will increase by 35 percent and the number of elders using long-term care will increase by 40 percent. All grim stats.

And then we have more and more people waiting for services. Nancy mentioned this. These are reports by states of people who will need residential services right now or in the next year. And as you can see, the number has just increased dramatically over the last few years. It basically has doubled since 1999.

And I want to show you one other thing, again that Nancy alluded to. We have had because of the American Recovery and Reinvestment Act, increased federal cost share over the recent years. In 2009. I shouldn't say recent years. And what that did was allowed states to buy a lot more long-term care services for people with Developmental Disabilities with less money.

So in 2009, the total expenditures of states went down by two billion dollars, while the amount spent for services went up by about three billion dollars. But look what happens now that the ARRA cost-share ends. If states maintain their present level of funding, when that cost share goes back down to its old number, we will see a decrease of about something over five to six billion dollars in expenditures for people with developmental disabilities. Now that is really scary.

Now somebody might say well that just takes us back to 2006. We have gone through a period of rapid growth. The reality is though that that reflects a tremendous cut in services.

And Nancy mentioned how we are really going to be strapped for people to provide supports, even if we have the finance for it. The line on the bottom shows the growth in our workforce in general. The three lines show projected growth in the number of workers needed to provide long-term care. I would ignore the outlier. That is the highest that anybody projected. But the two middle lines are probably a fair estimate of what is going to happen in terms of demand for long-term care workers over the next 40 years.

So is there over the next ten years? You know, I think it really depends on how seriously we keep our promises. One thing Nancy mentioned, we have got to focus on better family support and we need to ask questions about how the expectations on families will change. To what extent are people going to live with families longer? What are the increased roles for families in terms of how to support living? I was just in Ireland and in Ireland an awful lot of the group homes are five days a week. You know, it is not a concept in this country. You are there five days a week. You go home to the family on the weekend. Some of them are 52 weeks operating that way. Some of them are 48 so the family can have a vacation from the weekend support, too. But we need to think about models like that and then of course, we have really got to feed into family-directed creativity where families can come together and create their own little service systems either for an individual or for a number of people where a number of families might come around.

We have got to use our resources so much better. There is going to be real challenges in cost containment. We have got to be really intolerant of very costly models that provide more service than people need. We have got to start trading rules for reduced cost. We have got to move to more uniform and equitable systems of resource allocation. And then we have just got to create better access and equity. We have a system in which we just, where one of the primary principles of service is violated in terrible ways. And that principle to me is that no one gets more than they need until everybody gets what they need. We really have a rich system in this country for people with developmental disabilities by the standards of other groups of people with disabilities. We just don't use it as efficiently and as effectively as we can. And we need to recognize that what we are doing really poses -- Continuing to do what we are doing really poses long-term danger to people with disabilities.

And then I think we really need to think about who deserves access to this system and how are we going to assure that that occurs. And in many states, the people that I think about in that regard are people with autism.

Well, I will stop there. Thank you.

(Applause.)

Mr. Grossman: Thank you very much. We are going to now entertain questions from the committee. We are, I guess, about 20 minutes behind. So with hopefully not breaking too many federal rules, we will limit the questions to about ten minutes and move the break to right after that.

So when I recognize you, please identify who you are and we will take your question.

Dr. Insel: Good morning. This is Tom Insel. I am the chair of the IACC. I wanted to thank all three of you for excellent presentations. Much of what you were talking about were sort of long-term concerns. And it is very, very helpful to see those projections going out to 2020, 2030, and helping all of us to think about the policy implications. But to go back to the final presentation, Charlie, one of the last slides you showed was of real concern because it suggests that we are just about to go over a cliff in 2012, if I am reading this right, because of the change in the Recovery Act support.

Lee and Ellen began by saying that we are looking for three or four or five recommendations for what we need to alert the Secretary about in this arena. I wonder if the three of you could speak to this very quickly in terms of what we should be worry in about in 2012. By my read of your graph, actually the number goes back to where we were in 2005. You have already, all three of you talked about the growth and demand between 2000 and 2010. So by 2012, the demand is presumably going to be even greater. What would happen if we had a 2005 budget for the demand in 2012?

Dr. Lakin: Well, Nancy probably can answer that as well or better than I can. I think the problem with just looking at going back to 2005 is that since 2005, we have added 70 or 80,000 people to the service system. So in essence, it is far more complicated than going back to 2005 because there is a whole new -- the system is radically different in just those five years.

There are a lot of people that would really like the federal government to continue to support an enhanced cost share. I don't think this Congress is going to be in the mood for that. I think there are opportunities for states to use the money follows the person and other grant opportunities to sort of cushion what they are doing. And at the same time, you know, really, really improve their service system.

It is a huge challenge. And frankly, short of continued federal support, it is going to be really drastic at states because I think most people would say, at least for the next two or three years, even maintaining state spending at the level it now is is going to be a huge, huge challenge.

Ms. Thaler: Is it working? Yes. It is a serious issue and one that should get attention and it is getting no attention at all. I think because we think short-term in this last year, we went right down to the wire with an extension of the enhanced F map to take us to June. My guess is that the election last week delayed people talking or thinking about it because every house has changed, house and senate changes.

There is a presumption in the Recovery Act that the economy would recover and that this enhanced F map was to patch things together until states' economies recovered. We don't see that happening in very many states in time for 2012. So at a minimum, they should be monitoring and measuring each states' economy against those expectations. It may be true that a handful of states do recover adequately by 2012. It doesn't look like they all will. So there will need to be a federal remedy if states are not to dismiss people from services. I mean, people call it, the states call it the cliff.

Dr. East: I don't know how much I can add to that. We have used the term cliff ever since the Recovery Act funds were produced and we cautioned states and the federal government to really be conscious of the base funding for special education programs and other programs for people with disabilities because if the base funding is stagnant during the time that we have the Recovery funds, then when the Recovery funds go away, then there is the big cliff. And I don't see any way that we are going to avoid it in the majority of our states. The impact is already being seen with the downturn of the economy and the loss of state revenues for people with disabilities.

So we are in a big mess and we have got to all put our heads together and use our best thinking and our best partnerships with federal, state, and local governments to weather the storm that we are going to see here in 2012 and beyond. We say 2012 but we are thinking beyond, you know, several years in many states to adequately recover.

Ms. Thaler: Just a comment. I don't think we have a good picture of what has happened already. Many, many states have cut provider rates by five, ten, fifteen percent. States have laid off workers all over so there aren't people in the agency to manage services or develop any services. So even with the Recovery funds, there have been cutbacks and decreases in frequency and duration and states have taken certain services off their roster of available services. So we don't really have a picture of how severe it has been, even with the recovery funds, in order to predict what will happen with the future.

So, I think for your organization it is appropriate for it to be one of the issues because it is immediate in the next two to three years.

Mr. Ne'eman: So I --

Mr. Grossman: Identify yourself, please.

Mr. Ne'eman: Sorry. What? Oh. This is Ari Ne'eman. I have a question for Bill East and it actually builds on the discussion around this funding cliff.

It seems that the discussion around it so far has been around Medicaid and Medicaid funds. I am wondering if you could speak to it in the context of IDEA funds as well, just in the sense that the stimulus had a very significant increase in IDEA funds but, you know, as you know, school districts, if they are determined by their state education authority to be in compliance with IDEA, can cut their local maintenance of effort by as much as half of the funds that the increase in federal aid is.

So I mean, is there a policy solution that is being considered for that or when the special education, the increased Recovery Act funds for special education run out, are we also going to see much less money at the local level going to special education, as well as in regards to Medicaid?

Dr. East: I think there are huge issues around the maintenance of effort both at the state level and the local district level. There is more flexibility at the district level about what they can do. I think there is a major problem coming. The local districts were advised to spend their Recovery funds wisely to purchase those things that would have long-term impact. If you recall, one of the purposes of the Recovery money was for to keep people on the ground, you know, personnel and so forth. But the dilemma we faced with special education personnel, if you hired the personnel and put them in place, then now a couple of years later, somebody had got to maintain those personnel and that is a huge, huge problem for those districts that put all their Recovery funds in personnel.

So it is a major problem. I don't know what else I can add.

Mr. Grossman: I'm going to take the privilege of being the moderator here to ask the last question before we break.

But considering the fact that we have representatives of the two leading service providers for autism services in the country sitting here and one of the foremost thought leaders in research and disabilities, taking money off the table, which is a very, very hard thing to do, what other recommendations would you have, would you like us to make to the Secretary or is money the only thing?

Ms. Thaler: One is that the state DD agencies have no home in the federal government. There is no federal agency that relates to the DD agencies in the way the CDC relates to the Department of Health or SAMHSA relates to Mental Health directors. And so there is no federal initiative who train, support, give guidance, policy guidance on evidence-based practices for state DD directors. There is the only entity that state DD directors have a minor relationship with is the CMS. And so for the DD program to have a home in federal government for leadership and support might be one.

Dr. East: One thing that I would add and I mentioned it in my presentation very briefly about the concept of establishing communities of practice around autism and other programs promoting services for disabilities. I think we have got to do that. It is a recommendation I would have to the Secretary of HHS as well as the Secretary of Education. If we don't get people together at all levels and scales of federal, state, district, and school level working together, all stakeholders working together to resolve some of these issues, then we don't have a chance of making it in such a way that it is going to benefit the people we are trying to serve.

So stakeholders working together, sharing expertise, the resources, working on policy together would be my number one recommendation.

Dr. Lakin: Well, I would just say that families are the future. They have always been the future but they are the future now more than ever. And whatever the federal government can do to support families will be really well invested resources.

Mr. Grossman: Well thank you everyone. Since the --

Dr. Huang: Sorry, Lee. I didn't know our question period was so short. So, I am Larke Huang. I am from SAMHSA, Substance Abuse and Mental Health Services Administration. And thank you. Those were just terrific presentations. I was sitting in the back during your presentations.

So I have a boatload of questions but I just will ask a couple. One on the families' piece. It seems -- one. I will ask one. Okay.

On the families' piece, each one of you talked about families as sort of the key providers and I am wondering if there are any models out there about how best to support families. We often hear that families say that they are the army that is ready to work and they are the army that is there and they are doing it but they need support. So are there models for family supports which also includes family reimbursement, families as providers, an ideal sort of best practice models for families?

My second one has to do with the transition question that there was an interesting graph from Dr. Lakin about the percentage of young adults 16 to 29 in the DD System. But then do they go into another system after that and do we have a transition process for moving in to? I didn't see where those other systems were.

Dr. Lakin: Well let me start with the second one. This call for a seamless system is great but it simply doesn't exist. It is a horrible investment to provide special education to students until they are 18 or 21, depending on their -- or 25 even in some states, if their level of disability warrants, and then to have them really often sort of fall into this period of limbo in which they receive little, if nothing. Those are the people on the waiting lists, for the most part, people who have finished their education entitlement.

So it is extremely important that we take care of that. And there are states that really authorize entitlement after special education and, to some extent, deliver on it but it is not a national perspective that we ought to do that. So your call for a seamless system that goes across the lifespan is terribly important. It is a challenge because the systems are simply not connected.

There is some effort now to get rehab, vocational rehab more involved in transition and other adult service entities, too. But I would say it is so wasteful to invest so much in people's development and then not to follow through on those things that use that development and sustain that development in adulthood.

Nancy probably has a lot to say about that.

Ms. Thaler: Yes. Lots of states are doing lots of innovative things to support families who are caregivers, including paying family members. There are pilots, demonstrations, segments of programs. The difference I think between what is and what I am talking about is that a system be organized around that as its core paradigm. And that is a shift that states are now reckoning with. But lots of materials that I would be happy to share with you.

Dr. East: In the interest of time, I will just say one thing about transition.

It is so very important. And one of the things that I think the Secretaries can do and I would recommend is promote people talking together from the various programs, make sure that the seamless systems happen. It is not going to happen until they do.

And then we have examples of excellence around the country where transition is working good because people are sitting down and talking but that is not universal and the secretaries can do a lot to make that happen by their speeches and by their actions.

Mr. Grossman: I want to thank our speakers today. They have excellent I can understand why we have run long because we couldn't get enough of them. But if everyone can join me in showing our appreciation.

(Applause.)

Mr. Grossman: Well thank you all for your patience. Let's try and limit the break to ten minutes and we will resume at about five after. Thank you.

(Whereupon, the Subcommittee

members took a short break starting at 10:53 a.m. and reconvening at 11:10 a.m.)

Ms. Blackwell: Okay, I think we are ready to get started again. And I would like to start by introducing our next two panelists. To my right is Dr. Jim Conroy and I have to admit that I have known Jim for more than half of my very long lifetime. So we are good friends and colleagues and Jim is going to talk to us about self-direction, as is Mike Head who is here from the State of Michigan. And I have to also disclose that these two have worked together for many years also as partners and I think they complement each other very well.

And with that, I am going to let them say their piece.

Dr. Conroy: Good morning. I am Jim Conroy and Mike and I have switched places and that is because I recently went to see Penn and Teller and figured out how to do that.

Also, we are going to cover a great

deal of ground in a very short amount of time and that, too, is because we learned how to do that from magicians.

My task today is half of the task, which is to present a picture of the future of self- determination and self-direction models and the scientific evidence and then, in partnership with Mike, to shift right into how do you make these things happen in the real world? How can that happen in the state government? So our partnership is exactly that. I have been assigned on this topic for almost 20 years, beginning as a complete skeptic about self-determination and self- directed models.

So, I disclose that, too, as a scientist I started with a bias that this could never work, that it was nice rhetoric and nothing more. Now, I have published quite a few papers trying to claim that that person back then, that was my evil twin. So, I will present some pretty solid evidence and particular cost studies. So, here we go.

Historic trends, my outline, we will provide two points of reference. As I said, I will give one example in this case, just one example, of a self-determination story. For me, it is the seminal story that got it all started back in New Hampshire in 1992.

The scientific outcomes, a short version. The fiscal implications from five really decent studies that have been done now. The evidence is getting very compelling. Some definitional clarity. And finally, I will end on a note of optimism and caution, and then we will shift right into Mike's discussion of how this can work in the real world.

The Developmental Disabilities Act first passed in 1970. That is the year I got out of college and began work in this field. By the way, because of a chance acquisition of my first job, which took me to do a study of the Developmental Disabilities Act back in 1970 about how many people would be overlapping in their labels and what their service and support needs would be. And so I got to travel all over the country as a very young man. And the first place I went to was a place called Pennhurst Center, outside Valley Forge, Pennsylvania which is now well-known as one of the most notorious of our institutions and one that closed in 1987.

Autism was added to the Developmental Disabilities Act later. But until then and even now, conditions are lumped together. There is a great deal of confusion about diagnoses and the public has a terrible lack of understanding about the distinguishing features of all the labels that we have applied to people. So confusion is rampant and we won't change that overnight.

Large scale congregate care settings were the norm when I began and changes began in the '70s with media, exposes. Everyone knows about Geraldo and Willowbrook on Staten Island. But the first one was actually at Pennhurst, apropos of nothing actually, but in 1968 a local reporter in

Philadelphia did a five-night expose series on the conditions at Pennhurst. NBC then sent out a nationwide notice that this is a story. And so local stations all over America began to pick up local stories about their institutions in their own states. And that is where then Jerry Rivers, now Geraldo Rivera, got his key to accessing the situation at Willowbrook. And legal actions, of course.

I repeat Charlie Lakin's slide about the prevalence rates of autism labels by age, which I think are fascinating that the younger age groups are the hotbed of labeling people and that that decreases with age. But it is important to say that in the Developmental Disabilities field, which is the rubric under which so any of these big studies have been done, that people with autism and people in the spectrum are a significant part of the picture, although in many cases, they should not have been, that is how it is.

So with that, the trend has been in the United States for people in public institutions, large-scale congregate care, to increase sharply until about 1969 and then to begin decreasing, relatively gradually, compared to what happened in mental health, by the way, which was precipitous and based on drugs and very few services out on the streets.

Similarly in the early '70s, federal funding began to rise and community programs began to rise. And with the advent of community federal funding under Medicaid waivers in the early '80s, the growth has been explosive.

So we see now in our generation a decrease of reliance on large-scale congregate care settings and an increase in smaller community settings. That is our history. That is what our generation has done in this field, in large degree.

And again in history, we functioned on the medical model for the first century from 1850 onward, labeling, segregating, isolating. In the 1970s, we had a movement called #Normalization#. That was the spirit of the times. There were lawsuits and there was downsizing of developmental centers.

In the 1980s, person-centered thinking began to dominate the way we set goals with and for people and their families, individualized treatment. The IHP, the IPP, the IEP, the IWRP, all these labels for things.

I will never forget a father in Ohio who said, we have got all those plans. We have got an IEP. My daughter has an IHP, an ITP, an IWRP and we think we have been peed on enough. If you don't do one joke -- all right. Sorry.

In the new century, my perception is that CMS has begun to turn toward interest in self- determination, individual budgets, fiscal intermediaries, and all the models that have to do with self-direction. And what is that all about? Well, that change continues today and the question will be, what does it mean for public policy in autism? Is this relevant to all disabilities? Is it relevant in aging, mental health, developmental disabilities and the old mental retardation now called intellectual and developmental disabilities? I am going to contend that the answer is yes. And I am going to claim that the operational definition of these models is very, very simple, very straight-forward. It is about power. Fundamentally and ultimately about power. About whether people play a significant role in their own life dramas.

If power shifts, if people gain control over their lives and their own supports, and domain, and ultimately control over the money, then their lives will get better and costs will either decrease or stay the same. That is the operational theory of self- determination, as I have been stating it for 18 years now in all the research projects across the country. It is very simple. It is about power. It is about when professionals don't hold all the power but people and their allies have some of the power carefully, gradually, cautiously, properly. Yes, when people get more power, they spend money more wisely in more targeted manners.

And I will wind up this short presentation with a quote about that. A quick story. This was my skepticism coming to the four in New Hampshire in 1993 when I helped to write the original proposal for the self-determination funding from The Robert Wood Johnson Foundation. I said, look, what are you talking about shifting power? You have got to be kidding. Show me this with somebody in a coma. Be careful what you ask for because that is the first thing these radicals did.

Sean was in a terrible car accident and he was very popular in his high school and an athlete. And when he went into the hospital and after the acute phase was over, the professionals sent him to a nursing home but it was 100 miles away down in Massachusetts. And he was far away from his parents but it was the only one specifically designed for trauma, head trauma. So, professionals thought that was fine.

He didn't get much individual attention. He didn't improve and his care was costing about $120,000 a year. No one was very happy. Particularly, I wasn't happy when as again a young man experimenting with PowerPoint, I pulled out this clip art.

So families asked, isn't there another way? How much is all this costing? When they hear $120,000, really? Because if we had control of that money, we wouldn't spend it that way. Well, really? What would you do? Well, we would adapt a house for him. We would hire his high school friends to work as his attendants. We would hire nurses part-time to oversee his care but he would be with people who knew him and cared about him and we would have him close to us. That is what the family said.

So, courageous local leaders thought that might make sense. They explained the situation, advocated for it, and it became part of an experiment, while some officials were encouraged to look the other way. And then Robert Wood Johnson funded a grant and this actually came to be a reality.

And Sean actually got a house. There are many, many stories told about this, about Medicaid jail and how they bought a house and renovated it with Medicaid and everybody's going up the river and so forth and so on. But we don't have time for those stories but you can make them up yourself. This was risky business.

They put in a special bathroom. Friends were hired as attendants. Sean kept going out a lot. The family visited. The upshot of it was, as I saw it unfold over several years, Sean was busy. He was in a coma but the staff were his friends from high school and they were bored. They took him out all the time and they played music and they were busy and they read to him. They were bored and they got him out. Well, you know what? That was a lot more attention than he got in the nursing home.

So a few years later, Sean and his father appeared at the National Conference of Self- Advocacy in Rhode Island. And a lot of people think that what happened with Sean and his recovering of speech would never have happened if he had stayed in that nursing home with only a few minutes of direct contact with people per day.

So that original experiment in New Hampshire resulted in a national project The Robert Wood Johnson Foundation funded. And at the same time, Cash and Counseling began. Cash and Counseling is the same spirit, the same process for elders, for people who would rather not be put in the nursing homes, who would rather age in their own homes, or at least have a control over that average of $100,000 a year which we will pay to put people in nursing homes. And tonight my friend Eli Cohen says two million Americans will go to sleep in nursing homes. Most of them would rather not be there.

My generation, the Baby Boomers, we have got a fair amount of money and we are pretty cranky. And we are not going. So we really have to change the system except we don't know it yet. I just went to my 40th reunion of my friends from Yale University and nobody is thinking about it. It is going to come suddenly and sharply when we realize that America can't pay for it anymore and we didn't even want it. So there is a tidal wave coming and it is exciting.

Now a quick view of science. This is a measurement of person-centered planning, which by the way one of the only states in America that requires person-centered planning at the state level is Michigan and Mike heads the agency that is at the head of that. Person- centered planning, the new model that emerged in the '80s is really about helping people achieve what they want out of life. All of our services and all of our public dollars ought to be aimed at what kind of a life do you want, rather than the one that we have decided you should have? That is the whole deal.

So, did it increase in ten states with all this experimental project? Yes. Every place where you see a blue bar that is bigger than a red bar, we actually measured for more than 800 people in ten states, a couple of states' data work we didn't have baseline data, but we actually measured increases in the degree of person-centeredness in treating individuals. We can measure that. It is not perfect. No measurement is perfect but we have measured it. It actually is reliable. We have published about it and it works all right. So you can get a handle on person-center planning.

Did power actually shift? That is the second thing about self-determination. Did power shift? Yes, it did an average of say about eight percent and that is in a two and a half year period.

So, were we able to take small amounts of money in ten states with samples of people with significant disabilities and shift power toward them and their allies and away from professionals? Yes. Conclusively, yes. And these findings have been replicated by other studies. So, did power shift? Yes, it did. Can it happen in a pretty short time? Yes. Is this big? No, it is not big. Say it averages six or seven percent but that is in two years. What happens over ten years? What happens when you start this right after school at age 22 and continue?

Well, I really am, at this point, just completely eating my words when I was skeptical of all of this. I didn't expect to see any of these results but here it is. Quality of life: Do lives get better? Yes, people thought their lives got better ten out of ten states, each one statistically significant. And not even on here, we surveyed all the families in all the states and they all thought the same thing. In 14 out of 14 major life areas, they thought their relatives' lives got better and that is in a short time.

Now money, the third part. Did money go down or stay the same? Well, we had a study in New Hampshire in the beginning and needless to say, all of these are available in great detail. But for a quick overview, New Hampshire. Yes, costs went down between 12 and 15 percent and the New Hampshire agency used that on their waiting list. So at the end of the project, there was almost no waiting list. Small agency, rural area. Who knows if that would work on a large scale? But in Michigan, Mike and I published a paper in a book on self-determination in Developmental Disabilities. Costs went down six to nine percent, depending on how you estimate and what accounting methods you use.

In New Jersey, the same costs. Costs did not go up. We can explain why.

In California, all participants went up in costs over three years, but the participants in self-determination went up a lot less than the others. We had a control group. In New Hampshire and California, we had decent control groups. A very hard thing to get in social science.

In Allegan, Michigan, we did seven years of tracking the impact of self-determination and the cost-outcome ratios were fantastically different for the people involved in self- determination.

So the California slide is too much detail. I had better move right on. Was this ever replicated in the field of autism? You bet. In Pennsylvania, the youth advocate program contracted with us. The center for outcome analysis to do several years of outcome studies and absolutely, the overall quality of life as viewed by the family went up 15 points in a one-year period when they shifted models.

For the quality of life as viewed for the young person with autism, up almost 20 points in a short time. Yes, the self-directed models on the so-called wraparound models which are closely related in this implementation seem to be very effective and they have very strong outcomes. So with that, we have pretty good evidence now.

Is the self-determination and self-directed models, as my little part of this study, this process of science has been mostly in Developmental Disabilities, but it is going in aging with Cash and Counseling, too. It is very strong evidence and there are many names for it, lots of labels. And there will be a lot of confusion about this. My most familiar term is self-determination, which actually requires control of resources and I honestly have come to believe that that is key.

The other terms are multiple. Tom Nerney is working or has been working with CMS to try to bring some clarity into these definitional confusions. And the upshot of it is that people and their allies tend to spend public funds conservatively targeted buying what is needed for a life that makes sense.

Now, the caution at the end of my

chance to speak to you is we have made this terrible mistake before. We sold deinstitutionalization because we told people that it is less costly in the community. We sold it that way. And so states tried to save money that way.

California, in particular, created a community service system that was way lower quality than it could have been. California was spending about 50 percent of institutional costs to put people in the community. Every other state had spent about 75 percent. So California's quality in #Six-Pack# group homes was far lower than we saw in Oklahoma or Indiana or Pennsylvania. And we know that because we have measures comparable across all these states, across almost 8,000 people over 20 years. So we are pretty sure of that.

The lesson that I hope I would leave you with is that with the same dollars, we can produce better lives and better outcomes.

And finally, I end with my cousin

Buddy who is a billionaire. He started a cable TV company back in 1964 with a $2,000 loan and sold his company in 1996 for 11.2 billion dollars. And I said, hey Bud, not bad 11 billion. And he said it was mostly debt. I said, how much mostly debt? He said about five. Well, you know, I'm a generous guy. I said so do you need a few just to tide you over.

Well, I told him, hey Bud, I am studying this new thing. It is called self- determination. It is about the idea that if power and control of the public were shared with people, and their closest family, and allies that they would spend the money more wisely, they would spend less of it and they would produce better results. And I will quote cousin Bud here when he said, my billionaire cousin said, and I quote, #Well, duh!#

(Laughter.)

Dr. Conroy: Thanks.

(Applause.)

Mr. Head: All right, what do I do here? There is a trick to getting my slide show on here. Did I do it? Oh, there you go.

Good morning. Thank you for the opportunity to come and speak to you about something that has been close to my professional and personal heart for over 15 years. And I had the opportunity to introduce the first work we did in what we call self-determination in Michigan and I had the opportunity to be the state administrator for Mental Health and Developmental Disability and Substance Abuse Programs and I will give you a little feel for the path we have traversed over the past 15 years and what it has taken to try to put this into place in a state system. Because make no mistake, and most of you know this if you work at all on changes, but never underestimate the ability of people who have good educations, dedication, and commitment, to keep doing the same thing in the face of new facts and information.

And so certainly this is no

different than the work we did on deinstitutionalization and community placement back in the late '70s and early '80s in Michigan or the work we are doing right now to help promote recovery for persons with mental illness in our state.

Michigan is a county-based system. Our service system provides services or adults with mental illness, children with seriously emotional disturbance, as well as people with developmental disability, and they are all in the same organization.

We have been globally budgeted in our states since the 1980s, which allowed us to have our county organizations promote community placement options. In other words, we put the institutional dollars in the community mental health program operations back starting in the '80s and allowed them to continue to buy services at institutions or to provide alternatives. And so we have been very successful. We closed our DD center about a year ago. And we have one person left in an ICF bed. Nancy is supposed to go home on Wednesday. So then we won't have any ICF beds in our state And we are pretty proud of that and we think we have a good community placement system.

What has driven us to be able to do this is, of course, heavy use of Medicaid financing and in 1998, we were the second state to end up with a 1915(b) and (c) concurrent waiver arrangement. And right now, that pays about 1.9 billion dollars towards Mental health and developmental disabilities services.

In our state, services for people who are Medicaid beneficiaries is an entitlement. So for people with developmental disabilities, except for children who are not eligible for Medicaid, most people are eligible and that means we have no waiting lists. But I should express to you the fact that we have been building our system off the base of services we had, base of dollars we had in 1998, and although we do receive some increases, we don't get refinanced each year for increasing caseload. So we are probably going to hit a wall as our budget reductions that we are going to have make next year go into play. So I am not going to talk about that now.

We serve about 39,000 people with developmental disability through that concurrent waiver arrangement. About 27 or 28 percent of those are folks that are identified as people with dual diagnosis; people with a mental illness and a behavioral or a developmental disability diagnosis. And I counted them in here on the developmental disability side. We also have a separate fee- for-service children's waiver we have had since the mid-1980s and it serves about 460 individuals. In FY09 our DD Service expenditures were about 1.032 billion dollars, or about 47 percent of our expenditures in total.

With regard to self-direction, methods where people actually have control over money, they have an individual budget, they are able to select and hire and terminate individual providers, and otherwise retain agencies and work out other kinds of arrangements, we have about 3,500 or more in our concurrent waiver arrangement. I can't really tell you how many it is now. It has been growing a lot. We don't track it that closely. It seems to be an option. In most places, our goal is to try to get consistency across our system. We have some wonderful pockets of excellence who have done a lot.

About 25 percent of the individuals on the children's waiver operate their services on a family-directed model and about half or more than half of the individuals in that arrangement are families supporting children with autism.

There is a picture of Michigan. I always like to do it. you know, Michigan is easy, you hold up your hand. You know, I live there. I was born up here. This is Detroit. This is the thumb. You know, obvious kinds of things. We don't talk about the Upper Peninsula. Actually, if you go over to those four counties on the west, they are mostly Finns anyway. We don't talk to them very much. Well, they are nice people. I actually spent last week in Finland and saw a lot of people that looked like people who live in the Upper Peninsula. But if you notice where our 46 County Community Mental Health Programs are organized into 18 prepaid inpatient health plans and, generally speaking since Medicaid prepay arrangements are about 90 percent of our budget and going up obviously with the expansion of more people into Medicaid, virtually everyone in our system will be in the Medicaid program come 2014 and will work through these prepaid inpatient health plans.

But in Michigan, we have a number of things that have made self-determination or self- direction work for us. First of all, person- centered planning is a statutory consumer right. And some people say well it shouldn't be statutorily mandated. Well, it is not mandated in the same way you think because people have a right to a person-centered planning process and that is defined in statute. And it is a little different than saying you have to have a person-centered plan. That is not quite the same thing but we found that that basis has been important for the evolutionary work we have done here. We began that work in the early '90s as part of the community supported living arrangements and we built that into our statute in 1996.

Self-determination is spelled out in state policy. You can take a look at what the policy looks like at this link. We provide technical guidance and have for a number of years. We have a bi-monthly Self- Determination Leadership Development forum. There usually is 60 or 80 people in attendance. A lot of times, they are the people who are the true believers but we have gotten more and more people over the years. We try to help people deal with various kinds of specific topics.

We have this as a contractual obligation in our community mental health programs and PIHP contracts. It must be offered as an option for people. It must explained to them.

And we have strong advocacy support and I think this has been one of the things important in Jim's work with this group and this is a group called Michigan Partners for Freedom. There are actually some advocates who are involved with the Center for Self- Determination and some families who put this together. They have used some Developmental Disabilities Council money. We have given them a little bit of money but generally they go out and they help inform families and individuals about what self-determination arrangements really mean; and how to ask for those; and how to make sure that when you work with an agency, that you get what it is that you expect as opposed to something that is watered down. I can't say too much about that back-end advocacy. It really is important to drive the system. If you don't tell the people who are using the services and those closest to them what options they can expect and how they should go about advocating for that and helping each other, then the agencies themselves are not necessarily going to provide the kind of change that you want in some cases.

But we have a strong range of supports and services available through our Managed Specialty Services and Supports waiver. We use the 1915(b)(3) provision to cast a number of additional services under our 1915(b) waiver that served people who are not part of our (c) waiver arrangement with similar services and we have a broad range of flexible options available to people and we allow virtually all of those to be self-directed if a person chooses to do that. In some cases, that is relatively less meaningful than others.

Our state government leadership is

and has been committed to consumer participation and control. Both our previous state agency director in the 1990s and our current director of the Department of Community Health, which is a combined department, have strong support for this. We pull her out to talk about this at every chance we can. And federal support has been strong, too. The Olmstead decision and the Department of Justice enforcement help promote the use of options that give people personal control because it is easier for people to achieve an integrated real life that way.

CMS guidance and technical assistance has been outstanding over the last few years and, generally, there have been improved options and I am supposed to say DRA and ACA but I didn't get it typed very well exist in the statute.

Now we use the use the term self- determination as opposed to self-direction and I just thought I would try to differentiate a little bit underneath that.

Self-direction kind of are the acts of selecting, directing, and managing one's services and supports and it does involve managing resources that refers to methods that Medicaid beneficiaries generally are used and they are defined, I think quite well in the 1915(c) waiver template and again in some of the DRA options that were put into place. CMS has done a wonderful job of doing this and doing this in partnership with advocates and other people so that the kinds of things that CMS requires are the kinds of things that are necessary to make this work.

In our state, we call this self- determination for adults. We focus on the idea that self-determinations for adults, we don't offer it for families, we would call that family-directed services. We spent a lot of time on that in our policy discussions. It incorporates the methods of self-direction but we cast those with the principles of self- determination and I think Jim touched on these. But basically the principles are the freedom to brand one's life with meaning, rather than purchase some program pieces; the authority to control those resources in order to build a life connected to one's community and we try to promote the idea of responsibility for wise use of public dollars. And we promote the thinking around this with individuals, participants and with their allies. When we build our thinking, our policy off of this base and we think that is extremely important to give people a good sense of what the opportunity is here and, generally speaking, these options fit well within the kind of focus we put into our overall large waiver.

Now, the evolution of this, I think, is interesting. We started off as one of the 20 states who were participants in the self- determination for persons with developmental disabilities, an initiative that was offered by The Robert Wood Johnson Foundation.

We actually looked at Cash and

Counseling and decided we didn't need to do that. We had a consumer-directed personal care option already in our state and 98 percent of the people who use that service already have a consumer-directed option, although they don't have what you call budget control and we have had that since the late 1960s.

But we started with eight county programs and in 2000, we built in the family-directed services offered through the Children's Waiver Program and that was driven pretty much by family members who came to us and knew about those advocates and they were having a very hard time finding aides, especially aides who would provide behavioral supports when they used agencies. What they would find is that the agency rates, the rates that were being paid to individuals were pretty low. By the time an agency found somebody and got them trained, and tried to hook them into the family, they had gone and gotten another job or they didn't like that work and they left. So we said let's put this option into play and what families found was that by being able to find the people that would provide supports directly themselves. They could hire relatives, they could hire people from their church, their neighborhood, people who knew their child and would stick with them. And so people found that they had a lot more permanence with the staff that they hired when they could find them themselves, organize them themselves, and manage those staff themselves. And that really, I think, drove our children's waiver to use this option and, generally speaking, for people with behavior challenges, it is hard to find staff that will come and stay. And if there is a family relationship associated with it, that works a lot better. But we haven't given people control over our budget in the same kind of way that we do in the adult side of things.

In 2002, we moved to something called an application for participation. We had to organize our community mental health programs within the BBA requirements, these new creatures called Prepaid In-Patient Health Plans are what we had to be and so we put together a way for our county programs to apply for this because they had the first right of refusal. And in that, we required that they respond to the self-determination policy we had put together. We really put that together with CMS' bidding.

What you don't know is that we have kind of clashed with CMS right around 2000. They came to take a look at our 1915(b) waiver and we were going through our first renewal and they discovered that we were letting people control money, hire their own staff within this waiver. And they said well there is no provision for that within the Medicaid program. And we said, well, yes, there is. And then they kind of told us we shouldn't do this. And then we pulled out part of the Medicaid state manual that talked about how that is an option for personal care service that was already written in there and we had some back and forth kind of thing but the best thing that happened was we sent one of our folks, Glenn Stanton off to be the Deputy for Tom Hamilton at Disabled and Elderly Health Programs Group and then he got the job, so he helped put some of this in place.

And then there was Independence Plus and then there was the New Freedom Initiative and those all helped promote the thinking that went on. But one of the things CMS said to us in 2000, since they were uncomfortable with this, is they told us, we want you to write a policy and implement it on what self- determination is in your system. We also want you to explain to people what this model you use called the Choice Voucher Model. So we did both of those.

So we added that policy requirement to the contracts in 2003 and then we wrote something that was designed to beef up what we were doing with our PHPs called the Application for Renewal and Recommitment in

2008. And that basically has been a way to try to emphasize this. But even with that, we have inconsistency across our state with how much this stuff is offered.

And let me suggest to you that these are four considerations I think are important if you are trying to promote this in a state option. And one of those is to rethink whether you really want to offer this option as something that is part of your regular service planning and delivery process with your usual case management, or supports coordinators we call them, workers doing that or whether you want to try to set up an agency structure that is dedicated solely to delivering self-determination options and a couple of our larger counties have done that with great success. They set up entities that only do this kind of work that have people who only offer these options or not any confusion with a regular stream of options and people can take their service options over to these things, get a plan and a budget put together and get totally supported to have self- directed services, if that is what they choose, or only partially.

We think that is a real important thing. And actually once that got started in Oakland County about five years ago, three of our other large county organizations have kind of moved in that direction. It has worked well for them to get better penetration or options put on the table. We found and we don't do this as much as we think we should, but we believe that independent support brokers are key to this effort, that you need trained independent support brokers who can facilitate the best use of self-directed services. We also think that there is a lot to be said about person-centered planning. First of all, you have to understand it is a philosophy and it needs to be understood in your system but as a practice, it needs ongoing guidance and direction and it needs to be moved towards being person-centered, person-driven, and person-directed, and that gets back to individuals and families having a good understanding of what that is. But we know that when person-centered planning works well, that the plans and individual budgets evolve naturally from the person-centered planning process because person-centered planning is really about planning a life. And with people who know how to do that well, find it easy to put together individual budgets.

We also know that this doesn't happen enough. We try to promote it but often in the face of agencies having a million things to do, they don't do well with this back-end piece and that is, to try to find ways to have shared learning from people who have been involved with this option and understand how to make it work as comparison to people that are brand new.

So I wanted to go over a few things that I think make it work best. One of those is the supports coordinators who understand and embrace the policy option are the people that are going to get it done. Consumers have full information about self-determination is one of the first tenants in our policy requirements. Supporting interaction and assistance for those who are just getting started by those who are already involved is what I just mentioned. Facilitating the development of individual budgets usually takes an expert in a given agency. It is best to have one or two people with you are starting out that are good at this and can come in as facilitators, as a supports coordinator or a case manager is putting together an individual budget, don't try to take everybody who does a little bit of this work and teach them how to develop a budget because they probably aren't going to have enough intensity to start with and they are not going to get good at it. And usually this kind of work goes on in conjunction with whoever is managing your finances in your agency. So there has got to be some back and forth there. Otherwise, your finance people will just freeze up and they won't let people take money and have control over it.

We know that peer support and mentoring is important and we are learning how to do more of that. We have a peer support services option in our 1915(b) waiver and in our (c) waiver. And we have done a lot of that work on the side of persons with mental illness. We have probably got about 700 peer specialists that are running around Michigan helping people with serious mental illness but we are just beginning a peer mentoring model supporting people with developmental disabilities to be mentors and partners with other people with developmental disabilities and a lot of it is focused around helping people understand how to make an individual budget work, how to get your own life, how to develop your own place to live, how to maybe start a business, how to make work for you and so on.

We also note, as I mentioned, creative thinking in the PCP process is important. It is important also in the planning process to have open discussion and acknowledgment about conflicts of interest between providers and agencies that have providers but they are letting you have control over money and there is always a lot of conflict with that, including the allies that the person chooses are good.

And the last thing is leadership. We found locally that if leadership doesn't exist, not a lot will change.

Thanks.

(Applause.)

Mr. Grossman: Don Clintsman? Yes, in the interest of time, we are going to combine, if you don't mind, Jim and Mike, staying up here. In the interest of time, we are just going to move on to Don's presentation and then we will have the Q and A afterward.

Ms. Blackwell: And we should probably introduce Don. Don is with the Washington State Department of Developmental Disabilities and he is going to talk to us a little bit today about, or a lot I hope, about the standardized assessment tool that the State of Washington is using to help people with developmental disabilities. Thank you, Don.

Mr. Clintsman: You are welcome. Good morning and thank you for your interest in our standardized assessment.

I am going to give you a little background about who we are, what our assessment is about, what we did, and what we can get from our assessment. I am going to keep this pretty fast because I am supposed to only have 20 minutes and I am going to keep it at about the 30,000 foot level. So, hopefully you will get something from this presentation and hopefully I won't go too fast.

Just to start with, the State of Washington -- Sorry I am not used to a laser pointer.

The State of Washington started using this assessment process in June 2007 and it represented a significant shift in the way we were doing business, in the way that we were doing assessments, and the way we were authorizing services for people that we served.

So to give you a little background on who we are, the State of Washington has about 6.7 million people. Using a prevalence rate of what I think was 1.2, we assume about 81,000 people would be designated as having a developmental disability. We serve 39,000 people or we have a caseload of 39,000 people currently in our division.

That is about 12,000 people who are receiving services through one of our five home and community-based services waivers. We have about 900 people who are living in one of our five residential habilitation centers and there is no correlation between those numbers. That is just some weird symmetry that occurred as we were putting services together.

We have about 8,000 people who are receiving other services not on a waiver or through one of our facilities. We have about

4,000 children who are birth to three. And then we have 13,500 approximately who are not receiving a paid service from us at all.

So what led us to doing a standardized assessment, besides the fact that it is a really good idea? We had some performance audits in 2002 and 2003 that were pretty critical of the management practices of the division. They found in their performance audits that our assessment processes failed to link assessment to services. It found that our procedures governing assessment processes were poorly defined and were inconsistently applied. As a result, our policymakers were unable to determine if the services or the amount of funding we had for services was appropriate, inappropriate, or that the services we were providing was the right level of service or not.

Basically, without an accurate assessment, without an accurate assessment of service needs, without an accurate measure of the acuities of people, it was really impossible for decision-makers to know what our budget should look like.

So after extensive field research and analysis, it was apparent that our division's existing system was inadequate and that we needed to come up with a system that would assure that clients with similar needs would receive similar services.

So we had some expectations that were placed on us about what we should do. And we needed to build an assessment process that would measure the unique support needs of people with developmental disabilities. We needed to ensure that people with similar support needs would receive similar services across our state.

We also, just because of the size of the population that we were serving, we needed to have a computer assisted assessment. Coincidentally or maybe not coincidentally about the same time as we had our performance audits and the same time that we were starting down the path of making a standardized assessment, we also merged with another organization inside our department, with inside the Department of Social and Health Services in the State of Washington and that was Aging and Long-Term Care. We merged into what was considered Aging and Disability Services Administration.

And the aging side of the house had developed its own tool for assessing needs eligibility and services for people in personal care. And we decided that we would go with that technology, with that platform, for developing our assessment. That platform had an effective means of doing accurate assessment and service plans. It did accurate eligibilities. It was a structured assessment for determining risk for people in our vulnerable populations. And also the tool was flexible enough that we could add our particular -- What we needed to address our particular eligibility requirements for our services and our support.

So we had some challenges, as you

can well imagine, in trying to move forward. First, we wanted to identify a tool that would support our values and our guiding principles. And those principles would be that our system needed to support good outcomes for people in the areas of health and safety relationships, competence, inclusion, power, and choice and status.

Washington State recognizes that all people, including those with developmental disabilities have the capacity to be personally and socially productive. Children are expected to have access to public education, that people who are working age adults have a right to find work and to live independently.

We also have, like everybody, growing caseload and shrinking budgets. So we needed to come up with a system that would help us prioritize that increasing service demand.

We had legacy systems that we were using that were ineffective. We were using, I think, up to 26 different systems for collecting information on people for doing eligibility determinations for authorizing services. We needed to also figure out a way that we can migrate all of that information we have been collecting in a meaningful way into a new system.

We had a workforce that needed to be retrained to think about how we did assessments. We had 350 case managers that needed to learn how to work with a computer in front of them, when they are in the family home, how to go through a structured assessment, how to score that assessment appropriately so that, again, similarly situated people could expect the same outcomes from that assessment.

And then of course, we had some legal and litigation risks, whenever you start down a new path. We tried to be as transparent as possible, which gave, of course, our litigious advocates access to everything we were doing. Again, it turned out that we came up with a good process. And much of that was collaborative in nature.

So what did we do? We built a standardized assessment is what we did at the end of that. So what does it look like?

Our assessment has three different modules, really. It is the support assessment module, the service level assessment, and the individual support plan. Sitting over the top of that is our client details. And the client details, that is where we collect the demographic information, financial information, collateral contacts, client choice, those kind of things. And that client detail informs the other modules and they are all fairly interdependent.

So at a high level, just looking at the system and walking through the system starting at the left, a person comes in and has an eligibility determination. If they are determined eligible for being one of our clients, then we perform a support assessment. And the support assessment module, we will determine from that whether they are going to receive a paid service or if they are going to be on what we consider our no-paid services caseload.

So if they are going to receive a paid service, they will continue moving to the right to the service level assessment module and to the individual support level module.

So looking at the support assessment module, specifically, right now. It contains a common set of information about all clients who have received the assessment, which gives us the ability to do some data analysis about the population. It promotes consistency in that the assessment is administered the same way for all people. It determines ICF/MR eligibility, which is important particularly for the people who are on one of our five HCBS waivers because we have the requirement to annually do an eligibility determination of their ICF/MR eligibility. So, it is kind of an elegant way to put it into the assessment process.

This is also, again, as I said before, is where we determine the path for paid services and no-paid services and it is also where we gather the information for acuities that inform things like the respite algorithm.

The support assessment has four pretty interrelated elements to it. We do a support assessment for children. We do a Supports Intensity Scale for adults. We look at the exceptional medical and behavioral support scales. We look at protective supervision and we look at caregiver status.

As part of front end of the assessment, what we added was the Supports Intensity Scale, which was developed by the American Association of Intellectual and Developmental Disabilities and we chose that tool because it had some unique qualities to it. First, it is a tool that is standardized and validated and normed for people with developmental disabilities. It is a system that looks at the unique support needs that someone with developmental disabilities needs to achieve their goals or outcomes. It also added some credibility to our process because it is a validated tool.

The other thing is that it complements our residential and county service guidelines in the State of Washington in that it does measure the benefits and outcomes that should be afforded to all people with developmental disabilities.

The SIS also measured employment supports, which is something that no other assessments seem to do out there. And for us our working age adult policy, that was a fairly important element for our assessment.

And then again, this is a tool that is normed nationally and in fact internationally and so as more states start using the SIS, we have the ability to look at Washington State's data compared to other states and so it gives us a pretty good way to do some comparative analysis.

So I talked about the acuity scales

that are inside the tools. These are the acuity scales. We have activities of daily living, mobility, interpersonal, medical acuity, behavioral acuity, protective supervision and caregiver status. And then the bullets that you see underneath that really are the factors that contribute that determining an acuity scale.

The acuity scales were developed by our local experts for us to use in this tool.

So again, talking about the assessment, looking at the flow for that, we did the support assessment. Continue moving to the right for somebody receiving a paid service, we would look at the service level assessment module next. In the service level module, we determine what service path the person is going to take. So we have three paths. It will be waiver and residential, it will be state only, or it will be other Medicaid services.

This collects some specific health information that providers can use for developing support plans around the individual. It also gathers information programs, specific information that will inform the service eligibility levels and rates for things like personal care, individual and family support, residential services.

So again, once we have completed the service level assessment, then we move through to the individual support level module. And in that module, the purpose of that module is to draft a plan to meet a person's unique support needs. This is a collaborative process between a case manager or family and the computer. And not to give the computer any form but you know we all have our affinity for our laptops much like we do our automobiles, our motorcycles, and our spouses. And of course, the order is quite individualized.

So this process, the assessment information populates the service plans. So what we gain from the other two modules helps us to develop what support needs, to understand what support needs an individual is going to need. It looks at health and welfare needs. We have a fairly well automated process for being able to document health and welfare needs and to help us identify what the support needs will look like around that. It allows the planning team to look at the formal and informal supports to come up with a plan for an individual.

The ISP also is where we are going to identify the services that the division is going to pay for for somebody. And then this is a somewhat dynamic element of the tool. The individual support plan could be modified or updated as things change for the person over time.

And so what did this give us? It gave us standardized assessment with some significant benefits. First, it did address the values and principles. It supports the values and principles I mentioned earlier. It improved our work processes and support for case managers, in that we went from 26 different systems that we were using to identify health and welfare and eligibility needs for somebody. Now it is down to one system, one process. It improved methods to promote fairness and objectivity and that this assessment is very standardized. It is a very methodical approach for going through an assessment and talking to somebody about their support needs and what they need to be successful. It improves support and service planning processes because it had a structured way of determining health and welfare needs and support needs for an individual. It gave us greater accountability for public funds. It is ready access to client information for analysis. We can look in the tool. We can pull out information about the population and look at different things and help us make some decisions around service delivery and what is happening with the people we serve. And it also gave us some credible data to inform our decision makers, to inform our legislature and those people who are responsible for helping us build a budget to be able to look at this information and decide that what we are asking for probably makes sense.

So, just to give you a quick little like half a minute look at what kind of data we pull out of this and it is just very small, if our data were a mile, this is like probably a half inch of data.

So if we wanted to know, for example, how many people are we currently serving or how many people are on our caseloads who would have a primary diagnosis of autism or secondary diagnosis on the autism spectrum, we could pull that information out of our assessment so we could look at it. We can see that we have 1500 children who currently have a primary diagnosis of autism and about 2300 adults. And then we can see we have a few hundred other people with a diagnosis on the spectrum.

So if we wanted to know some things about that, we can take a look at the different acuity scales of the information we collected. We can see that for children that they have some pretty high needs for assistance in daily living, high needs around behavioral. They have some pretty significant needs in interpersonal.

And so we can look at it and we go, well okay, so how does that compare to the adult population or what do we need to know about these people perhaps as they age through our system and we need to think about our service delivery system and what we do. So if we look at adults, we can see they still have a high need in the assistance with daily living, the behavior scales, the protective supervision goes way up for people. And then when you look at the interpersonal again, it is very high.

So it can give us some pretty good comparative data to help us think about as decision makers what do we want to do for our system as we move forward.

So advice to our fellow travelers.

First, I want to say I missed it on this screen and probably the best thing you can do for yourself is find yourself a high-powered, a highly qualified project manager to help you go through this process. So if you are going to build a standardized assessment, you really need to involve your stakeholders. Involve clients, families, involve your business partners. Involve your staff and involve your legal advocates. You would also want to make sure that you do a great communication plan. Communicate often. Communicate well. Let people know what is coming; why are you doing this; where you are going; how is the information they are providing going to impact the outcomes. Also, you want to make sure you have good processes in place. You don't want to build a system around bad processes. Get good processes in place and then make sure that you develop good rules to support those processes.

And then you want to make sure that you solicit information from other people, from other states, from other organizations. And if you want you can contact me, I am Don Clintsman at Department of Social and Health Services in the State of Washington, and I will get you in contact with the people in our state who really know about this and who really understand our assessment process far better than I do.

And that is our story. Thank you.

(Applause.)

Mr. Grossman: Thank you everyone. Well, our attempt to make up some time has not been successful. So we will entertain questions now from the committee and let's try and limit this to ten minutes because I know people have that look in their eye when they want lunch. Ari, please identify yourself.

Mr. Ne'eman: Hi. This is Ari Ne'eman. Jim, I have a question for you and I guess the question could also be applied to the rest of you as well but I want to direct it to you first just because you raised in you studies around self-direction that you have used the measure of quality of life to assess that self-direction is consistently improving quality of life. Could you tell us a little bit more about what the inputs in those measures, in your measure is and what you use to assess that?

Dr. Conroy: Thanks, Eric. Probably for way too long the quick answer is there is one scale, one page, 14 areas of quality of life that people are encouraged to report in their quality of life on five point scales. Very, very simple. Very quick. And it turns out to be reliable even with children as young as five. So we have used it with folks with autism and folks with mental illness and people with intellectual and developmental disabilities and it works pretty well but now the footnote. Quality of life is multi- dimensional. No one measure is good enough. So we have independence, productivity, integration, satisfaction, family opinions, service intensity, self-direction, choices, choice making, quality of the environment. We have got measure upon measures and they all tie to quality of life.

But the answer to your question about that was there is a one-page scale that works pretty well and we have used it with about 50,000 people over the years.

Ms. Blackwell: Hi. This is Ellen Blackwell. I have a question for Don.

Once you implemented the standardized assessment process, did you find that it made a difference in your cost expenditures, Don?

Mr. Clintsman: I am -- I can't say that it made a difference in our cost expenditures because we were still doing the same amount of assessments. I think that we were identifying services for people that it turned out that in the end, we probably weren't that far off in how we had assessed people and the services that they were getting. So I could say that we had a significant increase. One of the things that we have noticed, though, over time is that now that we have been able to address more clearly the respite needs of individuals, that the respite needs have gone up significantly and more and more people are getting those services.

So I think we are going to see over time that the costs go up but I am not sure it is necessarily a result of the standardized assessment. It didn't save us money, other than it saved us some process in the field.

Ms. Resnik: Denise Resnik. Don, has your standardized assessment been replicated by any other state?

And then a follow-up question for Jim. I wanted to know the name of that 14-point scale that you referred to for quality of life. Thank you.

Mr. Clintsman: I can't say that our assessment has been replicated. I know people have been interested in what we did, particularly in the way that we used the supports intensity scale, along with our care tool to create our assessment. So it does give us a pretty unique way of looking at the support needs of a person with developmental disabilities.

Dr. Conroy: And the name of the scale is truly brilliant. It is called the quality of life changes scale. We hired a Madison Avenue company and years of work.

Mr. Ne'eman: But Jim, a really quick follow-up question around that. This is Ari.

You mentioned that there was increases on all 14 measures of quality of life. Which areas were there the most increase on?

Dr. Conroy: A great question because it differs according to the kind of intervention. For people coming out of institutions, the largest gain was privacy. For people getting involved in self-determination, the largest gain was control of my own life and second was relationships with friends. So, it is very,

very compelling kinds of stuff and it is self- rated.

And by the way, there are ways and ways to ask questions like this, particularly for people with limited language. And one of the worst ways to do that is yes/no questions. So we found a five-point scale works for various reasons in great ways.

And to come back to sharing the scale, I will send it to anybody anytime. Older versions are on my website and the latest versions are available anytime. So please, I will send them right to you.

Dr. Huang: Again, thanks for great presentations for Michael and Jim.

Mr. Grossman: Identify yourself.

Dr. Huang: Oh, Larke Huang from SAMHSA. I have a question about the -- So, the individual controlled their own budget, control their own funding. So how was that funding made? Was it a grant? And how was a determination made on what you would fund and how the expenditures were accounted for and things of that sort.

Mr. Head: Well, in our state, you develop a support plan and then you cost it out and that becomes the basis for the budget.

Now, it is more complicated than that, obviously. But generally speaking, you start with looking at what a person's goals. You start with taking a look at what their needs are. You try to find ways for them to achieve their needs and their goals within the scope of what they prefer most. And you are looking at preferences. You are involving allies and family members.

But basically you are taking the supports that they need and costing them out and then giving them control over that amount of money, as it were, so they can buy back authorized supports. Now, this is in a Medicaid environment. So services that people can directly manage are Medicaid authorized services. And if you want to switch your budget and have a service that wasn't authorized, you need to go back to the planning process and have a discussion about whether that service is necessary or not. But there is a lot of flexibility once you have a budget like that to be able to spend more on, for example, your personal assistance to incentivize the way that you hire and retain people, to transfer money, have flexibility in the budget to transfer money that you aren't using in one area to another area, and there is some give and take on the exactness of the authorization. If you understand that a plan of service is a plan, not an absolute, and that for many people plans get changed after the fact in order to meet what reality required. But that took some time for people to understand that because they thought a plan for a person with developmental disabilities or with autism was something that they had for life. It was always the same plan. It took a lot of work to help people understand how to change those. But it is basically an authorization to direct and spend Medicaid dollars, not to have cash in their pocket.

Mr. Grossman: Well, I am going to exercise moderator privileges again and ask the last question. And again, it is the same question I asked the last three panelists and that is to help us with our goals for this day, which is to come up with recommendations for the Secretary of HHS.

So, what would the three of you recommend? Don't all jump up at once.

Dr. Conroy: Well for me, it would be simple. Beginning as a skeptic about these self-directed self-determination models, I now can sit before you and say I stand corrected. And if I had one piece of advice for America right now, it would be to follow these models because they really do represent the future. Probably the largest human services in America is going to in-home supports, rather than out- of-home residential supports. If we give people what they need, it will be modest and cost-effective and it will fly with any political party.

Mr. Head: If you are trying to

develop models that really promote self-direction or self-determination, it is really important to understand how to put those together in ways that allow them to be supportive kind of in parallel but somewhat separate from your existing service system because it is easier to find true believers that will work in that system and do the kind of change things that are necessary. And if you don't base that on realistic use of person-centered planning, then you are to going to make a lot of progress with the whole thing.

Mr. Clintsman: I would just say that we probably need to make sure that we have a really good idea of what the supports and needs are of individuals. What is it that they really need? So that we are developing services and systems that make sense for people to look at.

I think it was James who said that a lot of bright people continue doing the same thing the same way. So, I think that really we need to make sure that we are developing the appropriate systems for individuals.

Mr. Grossman: Well, thank you Mike, Jim, and Don for your presentations. And I appreciate you sharing with us today and thank you very much for that.

(Applause.)

Mr. Grossman: Susan Daniels is going to have some announcements for lunch.

Dr. Daniels: Well thank you to all our speakers for an excellent session of talks this morning.

Today for lunch your options are the Twinbrook Grill, which is in the front of the hotel and it offers deli sandwiches and a hot buffet, as well as menu options. Although with our time, the menu might be a little bit tight. We also have offsite dining options and there is a list available at the front registration desk, if you decide that you want to leave the hotel for lunch.

I would also like to let you know for people who are on the conference call, we are going to be doing maintenance on the conference call during lunch. So you will have to hang up and call back in when we start up again around 1:15.

And there are parking stickers available at the front registration desk for those who need to leave the site.

Thank you and enjoy lunch. And we look forward to returning at 1:15.

(Whereupon the Subcommittee recessed for lunch at 12:19 p.m., and resumed at 1:21 p.m.)

AFTERNOON SESSION

(1:21 p.m.)

Ms. Blackwell: So welcome to our afternoon session. And with us now we have Kevin Ann Huckshorn, who is with the State of Delaware. Kevin is the Director of the Division of Substance Abuse and Mental Health. And she is going to talk with us today about seclusion and restraint.

So thank you, Kevin.

Ms. Huckshorn: Thanks, Ellen.

I hope everybody had a good lunch. My name is Kevin Huckshorn. And I am the State Director for Substance Abuse and Mental Health in Delaware.

Prior to that -- I've only been there a year and a half -- I was the Director of the National Technical Assistance Center at NASMHPD, where we basically helped with SAMHSA's help develop promising practices and did a lot of training, development, and technical assistance help, and assistance with all the states and the five territories.

One of the issues that we got involved with way back in 2000, after the new CMS rules came out, was the how to prevent conflict and violence that lead to the use of seclusion and restraint.

My talk is going to be a little bit different today in terms of the fact that I am talking to you about what we have primarily implemented in public mental health settings. Now, most of you know if you know anything about mental health settings that we have a lot of people with co-occurring disorders in those settings, but research has not been done specifically on populations of folks with intellectual disabilities.

What we have also found is that the six core strategies, which I am going to very briefly overview, that seemed to be a best practice, a developing best practice can be adapted to almost any population.

Just to begin, for those of you who maybe didn't follow this as closely as those of us in mental health did, back in 1998, the Hartford Courant published about six news stories over a period of several weeks detailing first the death of a young child, who died in restraints -- he was basically crushed to death -- who was in a residential treatment program in Connecticut.

The team of reporters that was sent out were quite shocked because, just like most people in the country who heard about this, they couldn't understand how a child could be sent to a treatment setting, where he was supposed to get care and services and supports and be killed.

When they went out, they found that the use of seclusion and restraint across the country were unregulated, were used very idiosyncratically, that almost no good data was being captured on it, and many times serious injuries and deaths were not even being reported to the appropriate people. So they came back and published this series titled "Deadly Restraint."

This series of newspaper reports caused such a reaction that within several months, this issue was in front of the United States Congress. Much to my somewhat shame, many of my colleagues basically called up their representatives and told them that this was sensationalist newspaper reporting and that this was not true.

So the U.S. Congress then sent out

the Government Accountability Office to see what they could find. They came back in about a year and published their report on seclusion and restraint and basically supported everything the Hartford Courant had found, but they also did one extra thing. The GAO report also included a scattering of model programs through the country that had managed to significantly reduce the use of seclusion and restraint. And they pointed them out as model programs.

Back at NASMHPD, when I got there in 2000, this was all happening. And many of the state institutions were really struggling. We have approximately 236 state institutions for mental health disorders in the country.

And because of the new rules and because of the scrutiny, CEOs were actually going to tell their staff, "Just don't touch clients anymore." And people were getting very hurt and staff were quitting. And it was not a good situation.

So what we did at NASMHPD is with

our partnership with SAMHSA, we were able to get some funding and hold a series of experts' meetings. And the ticket to go to this meeting was that you would have been involved in a successful seclusion and restraint reduction effort over the last several years.

Through that, those efforts, we found the six core strategies. People were doing kind of the same interventions to reduce seclusion and restraint, but they were calling them different things.

So that brings us to the development of the six core strategies and the next step, which is a SAMHSA-funded large scale study, research study, on the implementation of the six core strategies.

That started in 2004. It involved eight states. It was a three-year grant. And it was to measure the implementation of the six core strategies and measure the outcomes, what happened to our primary goal, which was to reduce seclusion and restraint, hours, and events.

The data was analyzed by a group in Cambridge. Some of you may know them, the Human Services Research Institute. These are the outcome variables included in the analysis. Again, seclusion had two variables and restraint had two. Both were the same hours and the number of consumers involved.

This was one of the tools that we developed to look at the six domains for the six core strategies. And they include leadership; debriefing; use of data; workforce development; tools for reduction; consumer, family, and advocate involvement; and oversight and witnessing, which was actually pulled out from the leadership domain.

In this process, of the 53 states that started, 10 dropped out because of Hurricane Katrina and a couple of other issues. Of those 43, 28 actually managed to implement the 6 core strategies and come to stable implementation, which looks like of like this.

On the left of the screen is where

you'll -- that's partly where training was occurring and we were setting up the actual research program. As the graph starts to increase, that is where the six core strategies are starting to be implemented. And every facility that did this had an organized plan of implementation.

And then they stabilized out at the end. So we did not include any of the other facilities, even though there were a number of those who had continued to implement throughout the end of the project.

The data showed that of the 20 facilities that reduced seclusion hours, 19 percent actually reduced the hours and 17 percent reduced the number of consumers secluded and 15 facilities reduced restraint hours by 55 percent in terms of hours and 16 facilities reduced the percent of consumers restrained by 30 percent.

Now, obviously, for those of you who are not researchers -- and you would probably think you'll be seeing numbers like

70 and 80 percent, but in truth, these are significant success story numbers that way exceed the kinds of success that you see in random clinical trials for most of our medications. So this was considered a very powerful outcome and set of data.

What that has done is now brought us to the point where we're trying to apply for an evidence-based practice through SAMHSA. And that takes some money. So we're working on that.

And Larke, who is here today, is kind of spearheading that effort. And I would like to thank her publicly. She has been wonderful to work with at SAMHSA.

So what we know now, at least in mental health, is that the prevention of conflict and the reduction of seclusion and restraint are very possible.

We know that multiple facilities in the country have reduced this use without any extra consultants or any kind of extra resources. We know that this effort takes a tremendous amount of commitment. You can't drop the ball.

It's not a couple-month project. It's more like a two to three-year project because your goal is not only to implement the six core strategies but to get them embedded in the organizational culture so they're not dependent on one person. All the staff and everyone needs to embed these because they are new practices.

And through the process of reducing seclusion and restraint this way, a lot of other opportunities become available. And we move closer and more forward in implementing the evidence-based practices that we know about but that often don't get implemented very quickly.

The six core strategies are based on a prevention model. And it's based very simply on this. If you can create environments of care and you can train your staff to interact with the people they're serving in a way that does not trigger them, does not cause conflict, then you can prevent the use of seclusion and restraint.

And, as you go into your facilities, what we found was that the majority of seclusion and restraint incidents occurred because staff had implemented a rule that a client either didn't understand or didn't agree with, that many of the rules that we have in our institutions are rumors that are based on history, are rules that are based on history, they don't have any real good sense to them.

It seems like one of the bad things about institutions -- and there are multiple bad things about institutions -- is that human beings seem to become very risk-averse. And what they normally do is create as many rules to structure the institution as possible to keep from getting in trouble.

And what those rules do, then, they're implemented idiosyncratically by sets of staff over shifts. And most of the people that are implementing the rules are sometimes our most least educated staff. So you have set up a real problem in terms of trying to avoid conflict.

So a lot of the six core strategies are based on primary prevention techniques. How do we create environments of care that do not have conflict in them? Now, obviously, that's a Pollyanna goal, but that doesn't mean we don't have that as a goal.

Secondary prevention strategies are strategies that we really implement to immediately respond when conflict starts to occur, when someone starts to be unhappy, when a customer starts to demonstrate they're not feeling too good today.

So, instead of the nurse -- and I'm an nurse -- sitting at the nursing station hearing a couple of people argue and waiting until they hear something thrown against the wall, they get up immediately and intervene. And they do that in a negotiating kind of style, a mediation kind of style, not an ordering parental kind of style.

And then tertiary, there's only one tertiary six core strategy. And that is debriefing, a rigorous analysis of what happened so we can find out and not have that repeated.

Trauma, informed care is another foundation of the six core strategies. And this is very simply based on the notion and the research that up to 98 percent of the people we serve in mental health facilities have significant life histories of trauma and through those experiences have often not learned how to emotionally regulate themselves.

It basically is a horrendous statistic. If you talk to the clients in the intellectual disability field, you will find similar numbers, although less research has been done, especially in institutions, where folks with ID tend to be abused more than in the community.

What we talk about when we talk about trauma, it's trauma informed care principles, which is what you implement along with the six core strategies and actually have been embedded in the six core strategies.

And they also understand that seclusion and restraint are violent, dangerous interventions. They are not therapeutic ever. They are basically safety measures of last resort, only to be used in the face of imminent danger, not maybe danger, not "Well, the last time he came in, he slugged a nurse. So we're going to do it ahead of time," imminent danger.

And, again, we have a lot of strategies on the different levels of violence and how to track that and how to teach staff when they must intervene and when not to intervene.

Interestingly enough, Andrew, who was the child that was killed in Connecticut, was killed because he refused to move to another breakfast table.

We have a lot of vignettes in part of our training, where we do kind of a psycho drama. I am just going to read just one item to remind everybody that our staff become very traumatized when putting hands on people also.

The first time that I helped with a restraint, a four-point restraint, I walked out of the room in tears because it was one of the most horrible things I had ever seen.

Now, I don't know about you all, but in mental health, we're having really hard times holding on to our direct care staff, especially our experienced direct care staff. They can go down the street to McDonald's and make as much money, and they don't get slugged. And they don't have to listen to a lot of rules. And they don't have to work night shift all the night.

So the issue of trauma is not only of critical importance for the people we serve but also for the staff who serve them. In a recovery-oriented environment, conflict and violence don't have a part.

And neither do seclusion and restraint. And I really like to look at seclusion and restraint in terms of goals to eliminate the use of it over the next 10 to 15 years.

And even though we do have settings where people in off the street and are often intoxicated and in those settings, we may never be able to completely get rid of seclusion and restraint, we still need to strive for it, just like we do for suicide prevention.

It would never be okay to say, "Well, we're going to reduce suicide attempts by 40 percent." That would never be okay. That's not ethical. So I think we need to move toward 100 percent with the knowledge that it is a process.

To start, we always ask facility leaders to develop a plan, almost like a treatment plan, for their facility. Most of our facilities have people in them that are very skilled at writing treatment plans. So we basically say, "We want you to write a treatment plan for your hospital on how to reduce violence and coercion in the use of seclusion and restraint and then take the six core strategies and flip them into goals with a series of objectives underneath."

I'm not going to be able to get in depth about this today because of the time, but I wanted to let any of you know that have any interest this is all in the public domain. I can send you articles. I can send you tools. I can send you assessments.

I can send you states that have -- very possibly your own state has done a lot of work, at least in the mental health piece of it, on this project. So I would be glad to do that. And I believe my information, my contact information, can be gotten from the people that are running the conference.

These are the six core strategies: leadership toward organizational change, using data to inform your practice, developing your workforce, implementing specific seclusion and restraint prevention tools, actively recruit and include service users and families in all activities, and making debriefing rigorous.

What we have found through the country is the most important strategy is the leadership strategy. We have probably trained over I would say probably 5,000 staff by now and in probably 46 states and in a majority of the public mental health institutions. And they have all gotten the same two-day training and the same guidance and the same access to technical assistance afterward.

And what we found is that the facilities that were able to be successful, the leaders were completely involved from the beginning. They didn't delegate it down. They didn't expect it to be some kind of grass roots effort where the direct care staff were going to just go ahead and do this on their own. This is definitely something that needs to be led by your CEO, your COO, your Director of Nursing, and your Medical Director.

Now, it is also, I will say, not necessary to have all four of those people involved. When we did this work in 1998 at South Florida State Hospital, the Medical Director said he didn't want any part of it.

So we said, "Okay. Then don't interfere, and don't sabotage." And by the end of the first year, he was standing right up there with the rest of us for the photos on the 89 percent reduction in seclusion and restraint that we saw.

So that's okay. A lot of people have been schooled in a different way. This isn't kind of blaming anybody for their past education.

I have been in school for years probably -- I don't even know how many years -- as a nurse. And I don't remember ever getting a lecture on seclusion and restraint. I don't even remember getting an informal discussion on seclusion and restraint.

So what the leaders do is they have to make violence prevention a high priority. They have to look through all the rules and regulations in the hospital and start getting rid of them, implementing different ways of speaking to people, to reduce and eliminate organizational barriers to look at their values and principles of the organization, and make the reduction of conflict and violence a number one principle, to reallocate resources sometimes, and to be able to hold people accountable for their actions after they have been trained, coached, and supported.

Some of the principles of effective leadership some of you have talked about today. Probably another huge one is the create the vision and live key values and using your values template to measure everything you do in your organization.

Using data. Using data is critically important. And by that I mean it is to get a baseline of use of seclusion and restraint before you ever thought about reducing it and use that as your baseline going forward, track yourself against yourself.

The use of seclusion and restraint is extremely sensitive to cultural factors in an institution. It is very hard to compare apples to apples, at least in the mental health field.

Every state is different. Every state hospital is different. Every culture is different. There is no one goal to reach. NASMHPD and the NASMHPD Research Institute have an aggregate number of average use for seclusion and restraint.

That is not a goal. That would be like adding all of us up in terms of our height and weight and dividing by our number and saying that was the idea height and weight. It's not. It's just a plain, old, regular number, even though some people have misunderstood it to be the goal.

Set realistic goals. Post these reports on each unit. What you will probably find if you do this is that you can have four units that look very similar. Three of them will be using seclusion and restraint rather regularly, and one won't.

And you will go on to that unit. And you will find out that you have a nurse or whoever is in charge of the unit who basically didn't ever want to use seclusion and restraint, got some training somewhere before she came to the hospital, and has quietly gone about getting rid of rules and regulations and changing things on that unit so it doesn't get used. And you can use that person to help you then go out to the other units and demonstrate what he or she has done.

Mandate data collection on seclusion and restraint events, hours, the use of stat medication because you do not want to see a decrease in seclusion and restraint and an increase in medication because that is chemical restraint, and also injury rates.

Your first question and your first comment is going to be that means injuries are going to go up. In fact, that is not at all true. As facilities reduce seclusion and restraint, their injury rates go down.

That makes sense because most times when you put your hands on a stranger who doesn't know you to make them do something they don't want to do, they're probably going to slug you. That's what people do. And they're not going to change just because they are in a hospital. So the less that happens, the less injuries occur.

Workforce development. There's a lot of work to do in workforce development, but probably the biggest issue is to make sure that they are pulled into this work, that they're given training, they understand how to de-escalate situations.

We assume they know how to do this, but research has shown that they do not. Our staff are not skilled in that. They generally think that de-escalation is meds or "Do what I say." And that's not de-escalation.

We have to put that in their performance evaluations and measure them for it. The job performance contract is a work contract. So if you don't have it in your performance evaluations for your staff, then it is unlikely they are going to be practicing it.

Just one comment about violence in mental health settings. Up until this last decade, violence in mental health settings has been blamed on the "patient" for years. Most all the research has been done to develop profiles of the dangerous patient.

What we have found when working in England and Scotland is that these findings are very variable and inconclusive. When you pull them all together and do a meta-analysis, you end up with no good data on anybody. So what that has basically told us is it's not the patient so much as the environment of care, including staff interaction patterns.

Staff education. And there's a list in here. And this PowerPoint will be available on the website they said in about a week. So there's a lot more information than I am going to go over today.

But, just to let you know, we have

a lot of training materials on many of these items, like use of prevention tools, matching interventions with escalating behaviors, creating trauma-informed systems.

Use violence prevention tools. These are things like assessing risk factors for violence in seclusion and restraint use. And, just to tell you, the number one risk factor for the use of seclusion and restraint on a new client being admitted is past use of seclusion and restraint or his experience having to be secluded and restrained.

We need to assess risk factors for death and injury against seclusion and restraint, especially restraint. Take-downs are very dangerous. If they are done without knowledge and medical knowledge to boot by staff who have not been trained or are not medical, people can die in less than six minutes. And you will have very little warning, especially for children who have asthma and have much more smaller frames.

Implement a universal trauma

assessment. Assume that everyone walking into your door has had traumatic life experiences, some of them probably in institutions of the kind that you are now admitting them to. And use crisis or safety plans that help us identify triggers and preferences with the client.

Use of comfort rooms. Incorporate person first language, which you all are years ahead of the mental health field.

Look at your training guidelines. There are about 43 vendors that we pay to come into our facilities and train our staff on de-escalation and the application of seclusion and restraint. If you are a manger, go to those trainings and find out what your staff are being trained.

I went to mine in Delaware just a year and a half ago and found that the trainers were using extraordinarily uncomfortable and even painful holds. They had all wrong information in terms of the newest literature. And they were spending most of their time explaining how to take people down, instead of how to avoid it in the first place. So we switched.

Person first language I'm not going to talk to you about because you all pretty much know that stuff. You led the way.

Hire people in recovery, family members/community advocates, and peers. We just hired eight peers in Delaware. We are using them to go out, talk to clients, debrief clients after events, do environment of care surveys. We have already found a whole list of things that we can: a) make more safe and b) make more welcoming in power and support participation.

And then debriefing, for those of you who are familiar with joint commission, debriefing is a shortcut root cause analysis. It basically gets everybody in the room that was involved and does brainstorming until you can go down to the root cause of why this happened and where did we drop the ball.

Every seclusion and restraint event

needs to be handled like if we had known more, we could have prevented this. And no stone should go unturned to try and figure that out.

It is not a blame session. No one should ever be blamed, nor should people be disciplined by the findings unless there was an egregious breach in policy because otherwise staff won't talk. And that, as you can understand, would be a normal reaction if they thought they were going to get in trouble.

This is a performance improvement process. Rigorous debriefing answers a lot of questions, almost like you were a reporter. It usually requires a new policy and procedure. It requires two specific activities: one immediately after the event and one the next working day, when the treatment team can be there.

I am only going to show you three more slides. The rest of these slides -- and there's about 30 -- are slides from facilities that have been very successful in reducing seclusion and restraint and all who would be very willing to talk to anybody about it. They're very proud of that work.

In Delaware -- like I said, I just got there. So we have really only been implementing for about a year. We really focused on reducing the hours allowed. CMS sets a minimum criterion of four hours for an order of restraint or seclusion. We dropped it to two. And we're going to drop it to one coming up.

And it looks very interesting across the country because when we first started doing this work, everybody in restraint or seclusion got out in 3 hours and 45 minutes. And then when Pennsylvania dropped it to 2 hours, everybody got out in one hour and 45 minutes. And then when they dropped it, they've now dropped it to 30 minutes.

So, again, it is an interesting social, cultural phenomenon, this whole project and this whole use of seclusion/restraint in institutional cultures.

We also focused on debriefing, holding the nurse managers accountable for unit behaviors, removing security staff, who would basically act like police, and replacing our restraint training model.

This is our numbers. We don't use seclusion a whole lot. We are a 200-bed facility. And these are for both the year 2008 and 2009. We significantly have been able to reduce restraint. And we have reduced chemical restraint by 87 percent.

This is South Florida State Hospital, where I started out in 1998. This is a 350-bed facility. We didn't know really what we were doing back then. So we kind of made it up as we went along. It took about four or five years. And it has been indebted ever since.

This is what the trajectory looks like when we started implementing. And then since March 2008, they have had a 96 overall reduction from baseline.

So I am going to stop here. And thank you very much for this opportunity. Hello to people on the phone. And, again, I am very available. And we have everything. Almost everything is electronic. So thank you for your attention.

(Applause.)

Mr. Grossman: Yes. Thank you, Kevin.

Questions? Stephen?

Dr. Shore: More just a comment.

Mr. Grossman: Can you introduce yourself?

Dr. Shore: Oh, yes. I'm Stephen Shore. And my comment is that this is just wonderful work. And we are really challenged to make sure that this education gets out to the people who know, who need to know the stuff and, you know, removing ignorance of how to interact with people who are different. So thank you.

Dr. Huckshorn: Thank you.

Dr. Huang: Thanks, Kevin. Always

a great presentation.

I have a question in terms of, what is your best guidance about moving this into other systems? We have had requests from schools, education, special education. What are your thoughts about that as a state person now?

Ms. Huckshorn: What I would do if I had a magic wand, I think, you know, for instance, for the ID, the people with intellectual disorders and autism, spectrum disorders, is I think I would get a nationally recognized group of people who are clinically based with some administrators, like just a group, a random selected group across the country that are recognized by their peers as being experts, and I get them in a room with the faculty that I've worked with for the last ten years and go through the training and have them basically comment and see where it can be adapted, where it doesn't work at all, and have conversation about that.

We have done some of that work in

small pockets of places, like we have had a couple of facilities that treat folks with intellectual disorders that came to our training, the six core strategy training, and went back and tried to adapt it, but it never got to a big enough tipping point where it could really affect the whole country like NASMHPD was able to do with your help.

So that's one thing I would do. I think I would divide it possibly into adults and kids because I think there are different needs there.

And I am certainly not an expert on autism spectrum disorders at all. I know what I know about developmental disabilities because most of our hospitals have a fairly large group of folks with co-occurring disorders in them. So that would be my first thought.

Mr. Grossman: Any other questions?

(No response.)

Mr. Grossman: Well, the same question to you as with the other panelists.

What recommendations would you like us to make to the Secretary?

Ms. Huckshorn: I think -- well, I heard a lot today about the strides that you were making about self-determination and implementing evidence-based practices, but I also heard that you had about 30,000 people still left in institutions, which is a lot less than we have, but it's still a large group of people.

And I really think that the folks in our institutions in most cases are our most vulnerable people. They are costing us the most money. Every day they're in there, we're institutionalizing them more. And our number one priority needs to be not to re-traumatize these folks.

It just -- that needs to be a priority. And I don't think we can ignore this. I know for years, even some of my colleagues in other states said, "Well, I'm not going to pay attention to the state hospitals because soon we won't even have them."

Well, that is abandonment, you know, to me of some of the most vulnerable people that we serve. And they deserve the time and energy that it takes to go in and try and make our treatment places as safe and sanctuary-like as possible. So I would elevate this if you identify this as something that you all need to work on.

And, again, I'm not an expert in your field. So I don't know what the data shows, but that's what I would call for.

Mr. Grossman: Thank you, Kevin.

Ms. Huckshorn: You're welcome.

(Applause.)

Ms. Blackwell: Okay. I'm going to introduce our next speakers from here if that's okay. Carrie Blakeway does a lot of work for CMS on the Direct Service Workforce. And she is here with Erika Robbins from the State of Ohio. Erika is CMS' Money Follows the Person Director. So she knows quite a bit about what happens when the workforce is trained.

So I am going to leave it to you, Carrie and Erika. And thank you so much.

Ms. Blakeway: Thanks. Thank you, Ellen.

That was a very sobering presentation to follow, but I think it underscores the importance of training and focusing on the workforce, the people that are delivering services. So I am in some ways glad for the segue, even though it was a little traumatizing, even just to hear.

So I am with The Lewin Group. And we have been operating the National Direct Service Workforce Resource Center for the Centers for Medicare & Medicaid Services for the last five years. And we have had the privilege of working with Erika in Ohio on her work with the Direct Service Workforce and training programs. So I am glad to have the opportunity to present with her today.

We have kind of combined our presentations. We are going to talk. I'm going to talk first about overall workforce challenges, which most of you are probably intimately aware of already, but just cover those really quickly, the importance of training particularly as an intervention to improve the quality and stability of the workforce.

We are going to hear from Erika about Ohio's experience. They have been very thoughtful and rigorous in their approach to thinking about training in their long-term support services sector. So you will be excited to hear about what they have done there.

And, then, finally, we wanted to make a few recommendations, which I have just put up here as a quick preview, too. We really think it's important that the Department of Health and Human Services understand the power that they have, really, in influencing workforce policy because they're funding most of long-term support services, almost half, through Medicaid program alone. And so that really sets the standard and drives quality within and without the Medicaid program.

And so we think, especially in home and community-based services, where this population is more and more receiving their services, it is important to really reward programs that implement good training programs.

We would like to see a strong partnership between the Department of Health and Human Services and the Department of Labor's the national network of workforce investment programs.

And, then, finally, we would like to see any workforce, all workforce initiatives. Similarly, I think we heard Billy say it this morning, too. It's important to not focus just on one population over another.

In looking at workforce, often this literally is the same group of people providing services for all different people to different age groups and with different type of disabilities. And so we really need to think broader with any type of workforce initiative. And so we would encourage the Department of Health and Human Services to do the same thing.

So, just quickly about the DSW Resource Center. It is a broad group of partners. The Lewin Group, Charlie Lakin, actually also is part of, his organization is part of, our team at the University of Minnesota Research and Training Center and Community Living.

We also have PHI, the Annapolis Coalition on the Behavioral Health Care Workforce, Westchester Consulting, lots of people with different experience doing workforce development in the long-term supports and services field, but remarkably kind of similar types of challenges, of course, across all of these sectors and similar strategies.

So we try to raise awareness as

much as we can about the challenges and then also the successes, the promising practices, disseminating best practices. And then we have been working really hard over the last few years, too, on trying to build consensus so that we can take more of a cross-population, cross-sector approach with everything that we do.

So since we started, CMS really asked us to focus on the Direct Service Workforce, which is actually not a term that I had ever heard at that point in 2003.

I don't think people really refer to direct service workers. They talk about direct care workers, direct support professionals, home health aides, certified nursing assistants. It is all of these folks that we are talking about, lots of different job titles, lots of different job classifications, working in different settings and institutions and psychiatric hospitals, in ICFMRs, in nursing homes, some of them working in institutions and home and community-based settings.

We decided at the resource center that we would really focus on home and community-based services, but a lot of the types of interventions and work that we're doing with states applies to institutional settings as well.

I started out thinking that there was this kind of paid workforce and an unpaid workforce that was providing these services. Its' not that clean anymore. There are certainly paid providers, sometimes self-employed individual providers, sometimes agency-based. Along the same lines, going hand in hand, you have family members, friends, neighbors, and more and more -- I'm sorry -- they're moving to be all paid support providers.

So we also are seeing more job classifications and categories that kind of fit under the Direct Service Workforce and kind of don't: transition coordinators, options counselors. Peer support specialists we heard someone mention today.

It's all kind of blurring now. You've got informal support providers being paid right alongside people that are caring for someone that they don't know, a stranger. So it's not very clean. So we end up kind of working with states to direct workforce challenges in lots of different levels.

So, really quickly, of course, we have what we talked about this morning already, a pretty significant shortage right now of workers. And it's going to grow even larger, the gap, just over the next 20 or 30 years.

The demand for long-term support services is growing at the same time that the pool of workers who are traditionally doing this jobs, kind of women in between the ages of 25 and 45, is shrinking. They're historically very low wages, few benefits, really high turnover, low retention. So these are huge challenges: lack of training opportunities and training standards.

I heard on NPR, actually, just yesterday someone talk about the challenges they had caring for their older grandmother and how they had to find one of these unskilled workers to come and help them around the house.

And I thought, "unskilled." This is often how we refer to this group of workers. And then I think, well, but we haven't trained them. So what do we expect? I mean, you have to invest training in order for people to have skills.

And so I think without the training, what we have often is an unskilled workforce when we know that this job requires a tremendous amount of skill and competency. And those have really actually been spelled out really well in a lot of different sectors.

The other problem which I see and I think all the members of our team would agree is a problem is that often workforce initiatives are undertaken to focus on one population.

So we have seen a lot of talk lately about the older population and the challenges of addressing the needs of our older Americans. And there was a lot of that embedded in the health care reform package with not very much discussion of that it's the same workforce. Often the same people are serving people of all ages and all types of disabilities.

So I think when we do that, it tends to fragment the system even more and we end up with lots of different rules and regulations that in some cases apply differently to the same worker depending on if they're working for different programs or in different settings. And I think that that can really be a problem.

So there are lots of different things you can do to improve the workforce quality and stability. More money, more benefits are probably the top of the list. We hear that the most. But I am starting to really see that training is pretty high up there.

Training in and of itself on the left side you kind of see in the ways that really have a positive impact on the workers. It improves their competence. It improves their flexibility in terms of where they can go and get a job.

The more training they have, the less likely they are to quit and go work at McDonald's, like Kevin was talking about. It improves confidence. And you know when you feel like you know what you are doing, you are much more likely to continue wanting to do it. When you go to work every day and feel like you're making thongs up and things are out of control, you're much more likely to quit. And that is kind of across sectors.

So just the competence and the increases in confidence improve job satisfaction. And it has been shown to significantly improve retention and reduce turnover, both in training initiatives that focus on the workers as well as training initiatives that focus on supervisors. Supervisor training has also been shown to significantly reduce turnover.

And then all of these things, of course, have a positive impact on the people that we're trying to serve, improve quality of services, and then ultimately I really believe that it lowers cost, too.

The cost associated with turnover is really staggering. And the fact that we continue to pay that and have just absorbed that I think is really shocking when we think of the lack of services and all the services that that could be paying for if we could invest a little bit more up front. The cost of turnover per individual is anywhere from 2,500 to 5,000 dollars every time someone is trained and leaves. And that is no small amount of money right now especially.

But there are lots of training challenges. So while lots of states and programs recognize that training is really important and that they want the populations that are being served to have the best trained staff working for them, there are really very minimal federal training requirements in Medicaid particularly and home and community-based services side.

So, really, the only two areas that there are significant federal training requirements are for certified nursing assistants and for home health aides that are working in the Medicare program for that 90-day acute care, post-acute care, long-term care.

State training requirements vary tremendously. So some states have expanded and added a lot more requirements. Others have the bare minimum of the Can and Medicare home health aides only. But typically, even with states that have beefed-up training requirements and expectations, they vary by program and by population. They're typically minimal in HCBS.

I think a lot of people assume when they sign up for a waiver that the staff that would be coming to support them would have some kind of training in home and community-based setting types of activities that are expected. And, for the most part, they don't.

I mean, often what they have had training in is CPR or it's very medical-based. They may have had the Can training but which is not really going to help them in terms of doing that independent living support, behavioral modification, social integrations, the things that we really would look to for someone to be providing, especially for someone who is living in the community and really trying to become more and more part of the community.

Very rarely are those competencies required. Some states have taken it upon themselves to work on those. We'll hear a little bit more about that.

And the reason why these aren't there is that it's just really difficult for states to pay for training. It's not built into their Medicaid programs. Because the services are tied to a particular individual, it's hard for states to make the case that the training is a service to this individual.

And so ultimately providers end up absorbing a lot of the cost of training. And they have to just pay for it out of the regular reimbursement rates that they get.

And so providers have come up with lots of different training programs and different ways to respond. And some have done excellent jobs, and others haven't. And they're all kind of working within the same Medicaid reimbursement rate environment, which doesn't allow a whole lot of flexibility in terms of how they pay for training.

So it's hard for the providers to pay for it. It's hard for workers to attend. Often workers aren't paid for the time that they spend in training. So when you're talking about very, very low-wage jobs to begin with, no paid time off, no benefits, it's hard to justify asking a worker, then, to take time off from their job to attend training classes. So this is another difficulty.

And, finally, there is this wonderful national network of workforce investment boards, one-stop shops. They have a huge well-established infrastructure for paying for training, for doing recruitment and retention activities, for helping organizations think about culture change. And, yet, they're pretty much completely disengaged from this workforce for very good reasons.

They have performance measures that they're trying to live up to. They're trying to place people into jobs with some potential and with some area for wage increases and for job growth. These are not those jobs.

And so it's been very difficult for Health and Human Services providers to partner with workforce investment boards and one-stops to take advantage of their recruitment capability because those one-stops don't want to recruit people into a field where they are going to end up on public support, where almost half of direct service workers are on some kind of public program, Medicaid or Food Stamps or something. It doesn't help them meet their goals in terms of providing kind of long-term career paths for the people they serve. And so that has been a very difficult system to try to engage.

One glimmer of hope that I want to make sure you all know about, in helping to engage the Department of Labor and their huge network of workforce infrastructure is a program that's called registered apprenticeship.

And, of course, apprenticeship has a long tradition in industry and other types of fields in manufacturing, but they have actually had, the Department of Labor Employment and Training Administration has now been offering these registered apprenticeship programs in this field for several years. There are four of them. There is one for direct support professionals that is just brand new in September.

They actually previously had a direct support specialist, but it's been converted to this direct support professional. It's based on the national alliance of direct support professionals. That association has developed competencies for people that support people with intellectual and developmental disabilities. And so there now is this apprenticeship program.

What the apprenticeship program does is provide a structure for training that's both on-the-job training and classroom training so that people can really take advantage of their time on the job as part of their training. It's experiential learning, classroom instruction. And then as you complete parts of the program, there are incremental wage increases that go along with that.

So this is very, very promising. The big challenge here is that this is a voluntary program that providers or states would enter into in partnership with the Department of Labor in their state. It's hard to make the case for them to want to do something like this if they can't be sure that they can fund those wage increases.

So I think while a lot of providers and states are excited about the idea of having a very kind of structured apprenticeship career path type of program, where are they going to come up with the money to do the wage increases?

So I think this has been one of the problems where as in other industries you can see how if a provider makes the bigger investment in their workforce, they're better trained, they can advertise that they have a higher-quality service, they can, therefore, get paid more, and this industry, the last part doesn't happen, the get paid more doesn't happen right now just because you have a better trained workforce. So it's a little hard to make the economic case right now.

But I want to plant that seed because I think we will hear a little bit more from Erika about maybe the potential of this. And I think there is a lot more room for this partnership. So I'll turn it over to Erika at this point.

(Applause.)

Ms. Robbins: Oh, it popped. It looks like most of my words are gone on the bottom of the page. I'll just tell you what it says, the secret at the bottom that you can't see.

We have had lots of strategies in Ohio. And I doubt we are unique in that a lot of states have strategies around workforce. And over the years, we have had multiple reports and recommendations and really thick documents that keep putting, you know, you do and then you put on a shelf somewhere and then in another couple of years, you do another one.

What we decided in the last couple of years is to really focus on more of an action-oriented plan, as opposed to just writing yet another set of recommendations.

And we had several workforce recommendations come out of the developmental disabilities system, what they call their futures work. We had the mental health system. They had a transformation state incentive grant. And they had some workforce recommendations. We also have been embarking on the unified long-term care system in Ohio. And there was a whole set of recommendations there.

And what we did through the Money Follows the Person demonstration is we pulled all of those recommendations together and came up with a unified goal.

Ohio was awarded the Money Follows the Person demonstration in 2007. And we basically developed a stakeholder system, a cross-diability council, basically, a cross-disability group.

And we pulled all of those recommendations together and came up with the following unified goal, which is cut off the bottom of the page: basically, working together as a unified long-term service and support system to lead the implementation of a comprehensive and flexible education and training system for direct service workers in all settings. This is not available in Ohio yet. It's a multi-phase, multi-year project.

Basically, in Ohio, we have multiple systems. And I think this is probably typical in many other states as well. The Rehab Services Commission in our state has personal care aides. They're not Medicaid-funded, but they are personal care aides. And they're funded with dollars through the rehab services side of the world.

We have the developmental disabilities world that has their own certification system. They call them direct support professionals. If you go to the Department of Health world, that's where our state-tested nurse aide stuff happens. That's where people who are working in nursing facilities get trained.

Then you have the ODJFS, which is where the Medicaid agency is. And we provide services to people with physical disabilities and children, a lot of children with autism.

And it's through that system -- we call them personal care aides -- a whole other set of certification and training standards, mental health, drug and alcohol, the aging system.

Each of these systems has its own certification and training. So if you are a direct support professional and you want to work in the aging system, you have to go through one system to get certified and you have to meet one set of training requirements. And if you decide that you also want to work with persons with drug and alcohol or mental health, then you have to go through a whole other certification set of standards.

So the occupational titles in training are very, very fragmented. As a state, when we step back and wanted to look at what Direct Service Workforce looks like in Ohio, we had a very difficult time looking at it because if you look at labor statistics, there are like three or four different titles that you can go under. And they cross. And it is very difficult to figure out where you stand as a state when it comes to where your need is and whether you have quality training in place.

Currently the only recognized system is the state-tested nurse aide suspended a lot through federal dollars. A lot of people that are working in institutional settings become a tested nurse aide.

We have a lot of home health agencies in Ohio who actually will send their aides through the state-tested nurse aide program. And they get that certificate. And then they are going to work in the community.

We know they are not getting training for community settings. They're getting facility-based training, which is not the same as working in the community.

It's the only place in Ohio where it's recognized and where there is actually a registry. And so you will notice that if you go to direct support professionals, personal care aides, all the other titles that I talked about a minute ago, you won't find any one place where you can locate a provider that has quality training.

What we want to do through the health and human service lattice project is actually pull all of that together. You want to kind of create this unskilled workforce and make it a skilled workforce.

We had conversations early on as we were working through the Money Follows the Person demonstration with our workforce investment people. And very quickly they told us "That's a dead-end job. We don't want to help you fund that. That's a dead-end job."

And we said, "Well, what if we make it not a dead-end job? Will you help us fund at least that core training that people need?"

And now they're starting to come to the table and recognize that if they can help us and if we start to connect the Direct Service Workforce to a lattice, whether it is training through to our college system or lattice across so that people can become the future managers in the system, that if we create a health and human service lattice, we're taking a workforce and making it a skilled workforce.

And we felt that it was important to recognize the human service side. A lot of times when you look at the state-tested nurse aide line or that pathway, you will see people going into the nursing programs.

And we have some community colleges in Ohio that will give credit to individuals that have gone through state-tested nurse aide training. And it's really just that nursing path.

Well, not everybody wants to be a nurse. Some direct support professionals in the system want to go into mental health counseling or maybe they want to go into social work. We want to recognize that people come into the system in a different place, that some people don't really have a desire at all to go into college. They just really want to grow from a management perspective and actually become the managers of direct service workers.

And so we felt it was important to create a lattice project that recognized a system of care that allowed people to be where they need to be at their time in life.

So what we have done or what we are hoping to do is to unify the Direct Service Workforce by first identifying the core, that there is a core set of skills that all direct service workers have.

For example, everybody should know how to handle emergencies. It doesn't matter whether you're in a community setting or you're in an institutional setting. It doesn't matter whether you're working with a child or an adult. You ought to know how to call 911. And so that would be an example of a core competency.

But not everybody needs to be specially trained in behavior support, but some people do. And so we want to create a set of specializations, such as behavioral support, mental health treatment, geriatric care, but there is a core and then on top of that core specializations.

So what we have done is we have developed a subgrant with The Ohio State University. And this subgrant is executed actually this month. And we have our first meeting on Wednesday. What we have asked The Ohio State University to do is to pull together a consortium of experts from across the state in all of our public universities.

So they are going to be pulling together a group of people that have experience in -- I think it's on the next slide -- secondary career technical education, long-term service support, social welfare, special education, health administration, public health, mental health, gerontology, labor market. All of these areas pulling those experts around the table to help us develop a health and human service lattice.

We have asked them as a university consortium to also come up with a set of research projects. As I mentioned earlier, data is not very good. You can't look at labor market statistics and assume that you understand what you're system is like.

So we feel like one of the first things we need to do is to conduct some research on what does Ohio's workforce look like, not just the Direct Service Workforce but where are our gaps in the health care delivery system?

We see direct service workers as the potential gap fillers. So if we have a shortage in mental health counselors, which we know we have a shortage in Ohio in the mental health side, we would like to take direct service workers and those that have interest and actually build them into that part of the education pathway so that they can become the future mental health counselors that we have a potential gap in in our current system.

And so we don't see it as just kind of the bottom layer but, rather, creating the health and human service model that is much larger than just Direct Service Workforce but grows into the health care system.

And then you will notice phase 2B of our project is to convene Direct Service Workforce roundtables. One of the things that we know is that we have some good things happening in Ohio.

We have some good training providers. For example, we have COALA, which is a training provider in Ohio that does a lot of training for the aging system. We have PATHS, which is another training provider. It provides a lot of services to people with developmental disabilities. And they're making excellent inroads and actually working with community colleges to award credit to direct service workers that are going through their programs.

So we don't want to start from scratch. What we want to do is to say "Here are all the great things happening in Ohio. How do we identify a core that doesn't cause us to go back ten years but, rather, to build on what is already working so that we can come together in a cross-disability fashion to build a health and human service lattice that works for all people?"

And so one of the things we want to do is pull together roundtables early next year to actually understand each other's systems and start to develop what that core looks like.

And then phase 3 of the subgrant is to actually start to create the modular content and then to pilot that content across the state with these same training providers that we already have in place in Ohio to make sure that the modular content actually works, that we are asking the right questions, that we are assessing the right skills, and then before we go statewide to make sure that it is working.

And then we will develop articulation and transfer agreements for the modules with the Board of Regents. We would like to see more than just a couple of community colleges in Ohio actually award credit. We would like to see all of them basically take on the experience of that direct service worker and award credit to a person.

And then we want to make that modular assessment available statewide and actually build it into a web-based front door so that there is one workforce center that people can go to.

One of the things that Ohio would like to really do is to really push self-direction, but it's difficult to push self-direction when we don't have one place that people can go to locate a provider. Right now if you want to hire a provider, you have to like interview 20 or 30 people and hope that you're getting the trained person.

But if we had a web-based system, if you're a family and you have a child with autism, you should be able to go to that web-based system and pull up a provider that has a specialization in autism. That would be the ideal state that you could go to that system and locate a provider that's been trained in that area.

And it would be great, even more so, to actually take some of the high school kids that are coming out and going into community college as well as some of our actual college kids and get them involved in direct support work while they're working on their training in whatever field they are trying to go into. So that way we're creating more of a social network so that people come out with social capital, as opposed to just that academic world, they understand what it is like to work with people with disabilities of all types.

And then toward the last phases of the project, we would really like to look at how Medicaid reimburses. Currently in Ohio, if you go back to the earlier slides, this one here, we have lots of different reimbursement structures. Some of those reimbursement structures pay for a little bit of training. Some of them pay for nothing at all.

And everybody is set up differently. The same direct support professional could go work in the DD system and get this rate and then go in the aging system and get a different rate. It's all different. It's all over the place.

What we would really like to do is after we build the modular assessment system, we would like to look at provide requirements under Medicaid and make sure that it matches the modular system and then set rates to pay for quality.

So that if you only have the core, you get a base rate. But then the more specializations you have, the more money you get paid.

And, of course, when you develop a

system like that, we have to also figure out how do you pass through dollars to employees of an agency because right now we pay an agency. And what we want to do is make sure that the money gets to the actual employee who has that specialization and that training.

So those are some of the things we need to figure out along the way that we want to start somewhere, and it's always better to start building blocks than to talk about it for another ten years. And so we want to start putting the plan into action. And then we'll start to figure out these pieces later in the phases.

I would say this is a multi-phase, multi-year project. We certainly can't accomplish this in the next couple of years. So we do envision that the The Ohio State University subgrant will exist for a while because it is going to take some building blocks to get to the phase 9.

I am going to turn it back over to Carrie to summarize.

Ms. Blakeway: So, as Erika was saying, this is a multi-year project that they have embarked on in Ohio, but I want to give her a lot of credit because, just to get to where they are, the agreement I think across all of these stakeholders and all of these different groups to even undertake something like this is enormous. It's so difficult in states to get these different agencies even talking to each other about what they are doing and sharing the information.

I think you all already have done a lot of the work towards doing this. And just having that consensus that this is what you want to do in that vision is huge.

And so that last phase that she talked about was what I was thinking about in terms of the registered apprenticeship. You know, Ohio is thinking about trying to look across all of their rates and reimbursement structures and figuring out a way to make sure that workers are reimbursed according to their skill and their competency and the quality of the services they provide. And I feel like that is an excellent candidate for something like a registered apprenticeship program.

But you could probably even do it without it. I mean, you are already establishing your core competencies in your specialty areas, but I think other states might be able to use that registered apprenticeship program as a platform to do something like this, to kind of seed that as an opportunity to engage a workforce investment system that hasn't really wanted to play with them before and to say, "Let's try to do this registered apprenticeship program and see if there are other ways we can partner going forward."

So three recommendations before Lee asks us. They are right here. Number one, what we would like to see is better mechanisms to pay for training through the Medicaid program. There just have got to be better ways that CMS and from a federal level, we can reward states like Ohio and providers, too, that have really put thought into training and developed good quality training programs that meet, then, good workforce outcomes.

So it would be wonderful if there would be some way that home and community-based waiver programs could demonstrate that they have shown such and such improvements in retention and turnover and in quality outcomes using maybe even the quality of life measure that we heard earlier this morning. And there are ways you can measure these things and tie that directly back to the workforce and to training.

And right now it is very difficult for states to figure that out, how to get those federal dollars to match to do that. So hopefully there would be some ideas there for ways to make it more possible through the Medicaid program.

And there has been such an emphasis at CMS recently on quality and home and community-based services in developing a quality framework. And, of course, we think that workforce is -- I don't know -- 99 percent quality from my perspective. It's a huge, huge component of it.

Number two, strengthen partnerships. There are already conversations going on, which we're very pleased to see, between HRSA, Health Resources and Services Administration, and Department of Labor as well as CMS. And Department of Labor, lots of more opportunities there, I think, to partner through registered apprenticeship programs because that kind of speaks their language I think as one of the advantages of that program.

But they have high-growth jobs initiatives that they could really use the support of people in the Department of Health and Human Services and just in the health and human services sector, I think, because they have goals that they need to meet.

And, of course, health care jobs are some of the fastest, kind of highest-demand jobs that they are really trying to improve in. So they could use our help. And I think there are lots of opportunities for partnership.

Finally, again, just a plea to look at any workforce initiative that the Department of Health and Human Services will be interested in funding and make sure that it's not following this fragmentation, this siloed system to really make sure that it's not to the advantage of one population to the detriment of another, that I think right now there's, like I said, a lot in the news about older Americans and the workforce needed to serve them. And I just think all of these groups need to kind of jump onto that and make sure that when we think about workforce for the older population, also it's that same workforce that serves younger people.

And I think we also need to think in that same vein about the family caregiver that's a part of this and think about training that makes sense in the context of self-directed programs, where the family member is becoming the paid direct support professional.

What kind of training do they need? It is going to be very different from the training of someone who doesn't have that experience. The family member may need little, if any, training. They know the person that they are supporting.

So I think we are going to have to really think carefully about how to make sure that training is flexible but then also meets the needs of all of the populations that we are trying to serve.

So, for more information, there is a synthesis of Direct Service Workforce demographics and challenges that our team developed and put out last year. And it really goes over the challenges in each of these workforce sectors, how similar they are and then the different initiatives that can be undertaken across all of them to improve the workforce and ultimately quality of services.

Thank you.

(Applause.)

Mr. Grossman: Thank you, Carrie and Erika. That was excellent. And you took some of my work away from me, which is even better.

So questions from the Committee? Denise?

Ms. Resnik: Denise Resnik. Excellent presentations and critically important for all ages on the spectrum. Are there some model training programs, curriculum development that you have seen that you would recommend that we explore?

Ms. Blakeway: Ohio's. No.

(Laughter.)

Ms. Blakeway: Well, there are for different populations, different sectors of the workforce. I guess there is a huge national training program that the University of Minnesota is affiliated with under the College of Direct Support, which is a web-based program that a lot of you are probably familiar with. And I think a lot of states are seeing that as a key strategy in their overall training program because, you know, especially in home and community-based services, the workers are so kind of disparate and spread out that having some kind of web-based platform to do training is a real good option.

But then there is actually a free program through the Volunteers of America that they developed with a grant from CMS. And it is an online training program. And then lots of good training programs have been developed by providers.

I think CMS is interested at this point in looking at what core competencies there are similar to the activity that Ohio is going through and then to really be able to compare training programs to see to the extent they're meeting those core competencies. And that hasn't really happened yet.

I feel like College of Direct Support has done so much work in validating their competencies, but then there are other training programs that we don't know. So it's hard to recommend specific ones.

I don't know. Do you have recommendations? Okay.

Dr. Huang: Is there any particular data --

Mr. Grossman: Introduce yourself.

Dr. Huang: Oh, I'm sorry. Larke Huang, SAMHSA.

Is there any particular data on that tenure of direct service workers, like how long do they stay in the positions? And I'm just -- you know, it makes me think back. In the late '60s, early '70s, we had a lot of paraprofessional workers. And that movement died out because there was no kind of career path for it. And the tenure of people in those positions was very short.

I am thinking your recommendation about the connection between HHS and Labor is a critical piece and we're really doing -- HHS is doing more work with them now, but, you know, they need to also see these career tracks and some data on the tenure of people in these positions.

Ms. Blakeway: Right.

Dr. Huang: Is that --

Ms. Blakeway: There is data. I think it really varies by sector. One of the things that I think is most unique about this field is that the highest level of turnover is in the first six months of the job. And I think that often has to do with people with very little understanding of what they're getting into and not very good expectations of what the job holds.

So some of the best interventions you can do are these realistic job previews or some kind of orientation that really shows people before they have signed on what they are getting into. So at that point they can bow out if they need to.

Once people get past the six-month point, then you can see all kinds of ranges. I mean, there are agencies we have worked with in Kentucky that their average tenure is like

16 years. I think it really depends on the population for intellectual and developmental disabilities.

You often see younger people for a few years. People in college get interested in doing this. For older populations, it's mostly older women, immigrant women that are doing this. And they are doing it part-time. And it's hard to track how long they have been doing it.

I guess that's another issue Erika pointed to is the data in this field are really slim because people often have multiple employers. They work part-time. No one is really keeping track of how long they have been in the field. They may know how long they have been for a certain employer, but it's difficult.

Dr. Rice: Hi. This is Cathy Rice.

Question for Erika. It is impressive that you have gotten all of the agencies to begin to talk together. Have you begun to address how you will actually fund the training programs or how that will come together?

Ms. Robbins: Initially through the pilots, we plan to fund it through Money Follows the Person demonstration balancing funds that we have earned through the grant. And then we want to as we are going through the pilot continue to work on that partnership with our workforce investment boards and our one-stops because we would like to see them fund that initial, the core training.

And so I think that gets us at least a starting ground to figure out what is the best venue to receive funds and how do we pass those dollars through. That is our plan at the moment.

Ms. Blackwell: We should probably explain that the Money Follows the Person demonstration is run out of CMS. And if you are interested in learning more about it, you can go to our website. And there is information about what states, including Ohio, are participating in the demonstrations. So that is what Carrie and Erika are referring to.

Mr. Grossman: No other questions. Thank you, Carrie and Erika. That was excellent.

(Applause.)

Mr. Grossman: Well, we are going to take our afternoon break. And we are going to start on time at 2:45. Thank you.

(Whereupon, the Subcommittee took a brief break starting at 2:33 p.m. and reconvening at 2:52 p.m.)

Ms. Blackwell: I think I'm going to go ahead and introduce our next speaker. We are missing Joe Wykowski at the moment. Oh, there's Joe. I'm sorry. Hi, Joe. Yes, come on up. Come on down.

And our first speaker is Sheldon Wheeler. Sheldon is with the Housing Resource Development Office of Adult Mental Health for the State of Maine. It's Department of Health and Human Services.

And Sheldon is going to talk with

us a little bit about obtaining housing under very challenging circumstances. And Joe is going to talk to us about what happens when housing is obtained.

So I thank both of you. And, with that, I'll leave.

Mr. Wheeler: This conference has been a real learning experience for me. I am glad to see a colleague from SAMHSA here. I think there are a lot of lessons that can be learned from the intellectual disabilities advocates. And funding sources and a lot of those lessons could be applied to adult mental health. I have been taking prodigious notes.

With that, I am going to be talking about independent housing vouchers. And I am going to be touching on I'll call it a boutique, HUH funding that's called Shelter Plus Care, which targets homeless persons with disabilities, principally mental health, chronic substance abuse, dual diagnosis, HIV/AIDS.

We also have a state subsidy

program through state general funds. I'm a little worried about that one as our state is facing a 20 percent projected deficit in the next fiscal year.

I have been lucky that through a struck of fate and business, I had been the son of an LCSW psychiatric social worker, and my mother is an English professor. So that makes me a good grant writer for adult mental health.

I helped to get this study that you see on the screen funded by writing a grant to the Corporation for Supported Housing that was funded by the Robert Wood Johnson Foundation.

I have always been a bit of a data wonk. Getting out of college and getting through college I subcontracted for IBM for about three years. And so I am pretty handy with a spreadsheet.

I am both proud and embarrassed to tell you that ten years ago my division was the only one in adult mental health that could say who they were serving, where they were, what their diagnosis was, how much rent they were paying, and so on and so forth. I am very pleased to report that we have come into the Twenty-First Century in the last ten years and our systems are greatly improved.

With that background, I have been able to demonstrate through data, data-driven decision-making, arguments to our legislature to increase the funding for our state subsidy program and arguments to HUD and our local continuums of care to increase funding for Shelter Plus Care.

I'm also proud to say that I just got word on my little Blackberry that we received 100 percent of the balance to state continuum of care funding for Shelter Plus Care.

Maine is perhaps the highest per capita rate of Shelter Plus Care in any state in the country. Over 62 percent of the continuum of care resources funded by HUD fund the Shelter Plus Care program. And it's about independent supported housing vouchers.

Now, a lesson that some of us learned either in school or through experience in AA is you first have to admit you have a problem. And we do have a problem. And we need to recognize that problem.

Nationwide the average wait time for people waiting for section 8 vouchers is about two years. And in some cases it can be as much as ten years.

A little anecdote. I used to call up housing authorities -- we have about 40 in our state -- 10 years ago, and I would say, "How long is your wait list?" Now I call them up, and I ask, "Are you accepting applications?" More than half of them are not. So we're not even able to document the need because the wait lists are closed.

According to the HUD report Congress of the worst case housing needs in 2007, there were 602,000 non-elderly disabled households. In addition, there were another 400,000 families with children who had an adult head of household with a disability.

These worst case housing needs were most prevalent among persons with disabilities. That probably comes as no surprise to any of us here.

Another little factoid I didn't want to throw out with respect to need comes from the Technical Assistance Collaborative, from their document priced out. The most recent one that I grabbed my hands on was priced out in 2008.

And it's a recurring theme in this document. There is not a single state or community or neighborhood in this country where a person on SSI can afford to pay the rent for a one-bedroom apartment.

In Washington, D.C., the amount of an SSI paycheck or an SSI check to cover rent for a one-bedroom apartment is 177 percent of that SSI check. In Vermont, it's 100 percent. In Maine, it ranges from 120 percent to about 87. I think the average in Maine is 96 percent of a person's SSI check can pay for a one-bedroom apartment.

I want to in looking at the importance of independent housing vouchers recognize and give a nod to the Supreme Court's Olmstead decision. I realize that was mentioned earlier. I think it is imperative we keep that on our radar lest we want additional class action suits at the state level.

With respect to Olmstead, there is also the issue of both civil and disability rights. And in meeting these needs, it is imperative that we recognize and reward mobility and choice within all of our programs.

There are actually some civil rights laws on the books. There are numerous civil rights laws on the books. But one I wanted to call out was the Fair Housing Act, section 808D. And that provides that executive departments and agencies shall administer their programs and activities relating to housing and Urban Development, including any federal agency having regulatory or supervisory authority over financial institutions -- I believe that means CMS; that is my own opinion, I am not a lawyer -- in a manner to affirmatively further the purposes of the act and shall coordinate with the Secretary of HUD.

We need to do a radically better job of balancing the resources dedicated to the sort of status quo of now group homes. Twenty years ago I would probably be saying institutions, but now I am going to pick on group homes.

We need to do a radically better job of shifting expenses towards individuals directing their own care, treatment, and housing. And I believe that is a civil rights issue. And, again, that is Sheldon Wheeler's statement. It's not representing my department.

Disability rights similarly, section 504, the Americans With Disabilities Act provides that, "No qualified individual with a disability should only by reason of his or her disability be excluded from the participation and be denied the benefits of or be subjected to discrimination under any program or activity receiving federal financial assistance."

We have really taken this to heart in Maine with the subsidy programs. And we have successfully utilized specifically Shelter Plus Care and honoring mobility and choice to allow folks to move across these somewhat arbitrary jurisdictional lines that the funding source often creates.

So when we go and apply for funding, it is usually for a particular county or a particular town or a particular fair market rent area. And if a person's natural supports move or if a person has needs relating to their disability to move, we let that happen through section 504.

I am going to promise I am going to do this in 20 minutes or less.

Consumer empowerment. I was really pleased to hear -- and this is what I can take back and learn more about consumer empowerment.

We in adult mental health are currently recognizing the primacy of independent housing vouchers as a foundation for recovery and hope. And we are empowering consumers by enhancing their choice, independence, and control over where they live and what services, if any, they receive.

This allows consumers to have their own successes, their own mistake. I think it's just imperative that we chip away at the "We know what is best for you" attitude and mentality that we still see today. And we have got a lot of work to do on that score.

I can't emphasize enough the choice, independence, and control, which is just such a critical component of independent housing vouchers.

These are American values I guess is the underpinning of my point here. It's not a Democrat-Republican issue. It is an American value to have choice, independence, and control. And just because a person has a disability doesn't mean that those values should be eroded or expeditiously removed.

The fourth element -- and I am going to use the "Duh" statement I heard earlier -- cost-effectiveness. Five days in an institution in Maine at $1,100 a day will cost more for housing than putting that person up in a one-bedroom apartment for a year, $1,100 a day in the institution, the housing cost for a year $14.63 a day, 14.63 a day versus 1,100 in the institution. That is assuming the person has SSI and is paying 30 percent of their income to rent the average one-bedroom apartment in Maine. That's my "Duh" moment.

There are some findings from this paper that I am going to quickly go through. I am going to jump to page 6. I call this a paper -- this was a subset of an actual study, academically focused and based. This is not.

This is a paper that I put together with my colleague Melany Mondello. She was the PI on the study because I helped to write the grant. I had access to the data and the tables.

And it turned out that about 75 percent of the people on the cost study that we did back in '09 were recipients of Shelter Plus Care. So I had the bright idea, let's drill down to Shelter Plus Care and see if there is anything going on.

And it was very similar to the results of the cost study that Melany and her colleagues produced in 2008. And they have since published two other longitudinal studies on this topic. And you can Google her name and get access to those studies.

This does look at homeless populations. So I still think that there is some relevance here. While homeless, the cost of services for this small cohort of 70 persons was 21,617 a year, average cost of services.

Once housed with a supportive housing voucher, the cost of services dramatically reduced to 12,808. The total cost of the housing in one of Maine's most expensive jurisdictions was 8,210. And I'm going to just point out a couple of interesting little factoids here.

There is a 34 percent decrease in health care costs, 43 percent decrease in mental health service costs, 49 percent decrease in ER costs, 51 percent decrease in ambulance costs. There is a pretty little chart of that.

Now, what is fascinating is that concurrently there was a 64 percent increase in substance abuse treatment contacts, 311 percent increase in transportation services, 18 percent increase in mental health service contacts, 40 percent increase in case management.

So what that is telling us is that the care being delivered, the appropriate care being delivered, in community settings increased. And the cost of that care decreased when compared to a state of homelessness, getting ER rides and police rides, ambulance rides and police rides to the hospitals. The housing was a tremendously stabilizing factor. And that is the graph.

The most dramatic findings had to do with the mental health inpatient hospitalizations. There's a 53 percent decrease in the cost and a 35 percent decrease in the frequency.

And what was the biggest surprise for me in this study was the physical health inpatient hospitalizations. That was hardly on our radar when we were mapping this out. And we had a tremendous success with the hospitals, the Medicaid payment system.

Usually the Medicaid payments, from acne to zits, podiatry to psychiatry, went through my office. And so I have access to the Medicaid records. But we got a lot of cooperation for this study from the local hospitals and service community as well, but there is just an incredible decrease in physical health and patient costs and frequency. And there we have that mapped out.

I'm going to shift gears a little bit. And I want to jump right into some findings and conclusions. The findings in the study, I would ask you to look at the second bullet. We determined that it cost 41 percent less to provide services to persons using Shelter Plus Care, that housing voucher, rather than providing services to persons in a state of homelessness.

One of the conclusions that I would also like to highlight for purposes of this conference is the need for more influence on statutes, policies, rules at all levels and to pay a lot of attention to where we put that influence.

I spent four years working with the Maine State Housing Authority to get a priority for persons with mental illness on their section 8 administrative plan.

We have 40 public housing authorities. I worked with one. It took me four years. I will be long since dead before

I hit every public housing authority at that rate.

HUD currently has at the federal level some rulemaking that is available for comment through the end of the month on a national housing trust fund, which I believe HUD is seeking a billion dollars in funding.

Now would be a wonderful time to comment to HUD on that rulemaking process as the public health Care Act gets implemented and there are opportunities for rulemaking, I think we as advocates in a community need to jump on those processes.

Coming from state government, we usually don't open up our Medicaid policy and state plan to rulemaking very much because when you do, it's quite a lengthy and administrative process. And, lo and behold, it may expect you to actually change the system. So when systems do open up for a rulemaking, take advantage of it.

I am going to try to wrap this up now. I really like the concept of Money

Follows the Person. As that gains traction at CMS, we need to ensure that the resources linked to the care under MFP also include resources linked to housing.

We are beginning to realize that access to safety in affordable housing is a medical necessity. Independent housing vouchers deliver real therapeutic value. They promote consumer empowerment. They're supportive of both civil and disability rights. And they're demonstrated to be radically cost-effective.

Recognizing this, I am suggesting that we look to the medical value of independent housing vouchers and the need for a prescription of housing. And I have handed that out to you from Dr. James O'Connell of Massachusetts General Hospital, who wrote, actually, a prescription for housing. I think that is sort of a paradigm shift that we need to adopt and recognize the value of independent housing vouchers.

Thank you.

(Applause.)

Mr. Wykowski: Good afternoon. Thank you for having me here this afternoon.

I am Joe Wykowski, and I am the Director of Community Vision. We are an individual support agency that has been providing support. We are in our 22nd year.

So I am here to talk about housing this afternoon because I have been spending quite a bit of time working with other states and coalitions on how to access housing for individuals with disabilities. But I have been involved on the support sides for people for a lot of years now. And, really, we need to separate them both, but it's hard to talk about one without the other.

So we spend a lot of time supporting individuals to live in their own home and helping people figure out how they're going to hire individuals to support them. And that goes for people 24 hours a day to people who might have supports 2 hours a day or 10 hours a week or such.

And one of our key values is that people are on the lease. They have their lease to their home or they own their home. So Community Vision does not own any property. We want to make sure that people have control in their life and they're in charge.

A lot of Sheldon's comments are perfect. They're very pertinent this afternoon because I am going to talk about some of those programs real briefly. This is what sometimes is a six-hour presentation in resources in 20 minutes. So I will just give you a little taste. And then I will be happy to post other information on the site and that type of thing.

So we have in the past most commonly used the section 8 voucher to assist people to live in their own home. This is Catherine with her mom. She has her own home that she lives in with a voucher.

It's true there are waiting lists. Sometimes the lists are closed. But over our 20 years plus of time, we have really encouraged people to sign up for those lists. And we have many, many people who have the section 8 voucher. And it's wonderful because it's very portable because people can live wherever they want to live.

Catherine happens to live in, actually, her original family home. Her parents moved out. And she rents from them. And she rents in her original family home because she knows her neighbors and she knows her neighborhood and she gets a lot of support from her neighbors. So this made a lot of sense for her family.

And she lives in this wonderful house in Southeast Portland or Portland, Oregon on the other end, the other coast. And it works very well for her.

So, although we have some trouble with access and, as Sheldon mentioned, we want to keep advocating for more vouchers, I think it is a wonderful program and something that we need to keep hooking people up with and always remind people to be on the waiting list. And so we diligently assist individuals and families to make sure that people are signed up.

Another type of rental housing that we have assisted people with over the years is project base. And, again, these are federal HUD monies, but, instead of someone getting a voucher, it is connected to that project created by the local housing authority. And so we have helped people by waiting lists to seek out those housing opportunities.

And this is Russell, who lives in this wonderful studio apartment in Portland and, again, pays. He pays 30 percent of his income to rent, as Catherine pays 30 percent of her income with the voucher, so maybe a couple of hundred dollars.

We are very clear that housing is a human right and a value. And we got into this work with housing because we had to by necessity. We literally started with people moving out of our state institution over 20 years ago, when people needed a place to live.

So we had to get creative about where people would live. And I am going to show you a couple of other examples of how we do this with rental housing.

One of the other ways, other than the typical federally funded programs through the public housing authority, like the voucher or like project-based housing, we assist people to hook up with development initiatives. And these are nonprofit housing organizations, sometimes private but mostly nonprofit, creating housing with federal monies.

And a lot of our work is really relationship-based. We need to continue to get out there in the community and to emphasize that people with disabilities want to have their own home and that we want funding to work in that manner.

And I have found all of our public nonprofits and other developers very open. We found that no one had ever just come and basically done the ask. What we had asked for in the past was to build 15-bed or 12-bed or 10 or 6-person group homes. And when people understand that people want that right to housing and their individual housing, it makes sense to people in the housing field.

So we have realized that often in social service, we were kind of in our own way and that housing people have welcomed us with open arms and creating these initiatives.

So we work very diligently with nonprofit housing developers; CDCs, or community development corporations that are in every state, that are in every local area; community action organizations; and economic development corporations.

And this is a friend of mine, John, on the left side, in the lower left side, with his circle of support. He recently celebrated his 75th birthday. He was actually a homeowner for a period of about 12 years.

And he hit retirement age at 72 and actually sold his home. And we'll talk a little bit about home ownership in a minute.

And he took his asset and bought a van so he could do a little traveling because he wants to do that retirement thing. And he has a personal needs trust. In fact, he is going to Cape Canaveral in February, wants to see the last space shuttle launch.

And he currently lives in this wonderful housing. After he sold his home, he went and rented some housing from the Portland Development Commission.

So, again, there are many nonprofit and city-driven and local county-driven housing initiatives and possibilities for people that we don't even know about sometimes.

And so by creating these relationships, John was able to get this home for about $425 a month in rent. So he went back to being renter, which some of us might choose to do at retirement age or we might stay in our homes or downsize.

But all of these initiatives exist out there. And the great thing is that they're all generic. They're not disability-based again. These resources are out there.

There's millions of dollars already in local counties and cities available to help people with renting or to help first-time home buyers.

And they're not just tagged for people with disability. We also spend a fair amount of time helping support people with finding rental places or with home ownership.

This is Arlene. She is an artist. And she has a co-facilitator with her art work: Patricia. And she is here with some of her ribbons that she received from the Loma County Fair for her art work. She has rented for years using -- she actually has some money that we used through the Medicaid waiver.

And so one thing that individuals don't always know in different states is that there is a portion of the waiver if you have a live-in roommate without a disability that you can use for part of the housing payment in utilities.

So we used this fairly extensively for the last 20 years. So it's a proven strategy for those folks who want to have a live-in roommate without a disability.

And what we gain out of this is great relationship for people. Here is Patricia and Arlene. This is one of their art projects they're working on together. It's called "The Wedding." And they have a number of sculptures they have worked on together and other art work.

They live in this wonderful apartment with the waiver. And, again, a piece comes from the waiver. A piece comes from Arlene's wages. And a piece comes from her Social Security income.

Everyone we're supporting lives on a tight budget, but they're really good at managing their budget, both in rental and home ownership.

And this is a picture of her wall that she has decorated. Her whole apartment is decorated. And so we really need to continue to think outside the box about assisting people with disabilities, people with autism to have relationships with other people and, again, not just by grouping people and to get creative in how we brainstorm with families and our other allies and how to create mixed housing.

It is so easy to just kind of work toward the numbers and say, "Let's just build larger places because a lot of people need housing," but we really need to work on the quality one person at a time. And I know no other way to do that.

When we started 20 years ago, we literally started with one individual and one family. And today we are supporting 75 people, all, again, living in their own places.

One of the other things we utilize for people, just a side note, for both home ownership and employment -- we have talked about employment a little bit today -- and for future education, or IDAs.

So we have a program called Future Assets for Independence. And it's a matched savings account. And in cooperation with another nonprofit in Oregon, we are able to provide a five-to-one match up to $5,000.

So in this example, Arlene is using her money to promote her art business. And she will fill that match money soon.

And then the money is held at another nonprofit. It doesn't affect your benefits. And so when she wants to rent some space or create marketing brochures, she will flip from the IDA account. If she wanted to open one in the future for home ownership, she could put together $5,000 to purchase a home.

So stuff that we find and we hope you will find very exciting, different ways to create assets for people. And, again, a lot of this money is already in the community through banks and social service agencies.

So the home ownership piece. We talked a little bit about rental. Again, I said it would be quick. We have something called the Home Ownership Independence Project. We help 10 to 15 people back home a year buy a home. Some are supported by Community Vision.

We also help a lot of other people with disabilities in the community buy a home and other families if they have kids with disabilities. And I will show you a few of the resources we use.

But we really like home ownership because it really gives people control to live where they want. They can sell in the future, like John, who you saw on the slides, if they want to. They have an ability to acquire an asset.

So we really believe that people with disabilities don't need to live in poverty, that we all have a right. It is an American right to have a good housing, to have assets in our life, and to create some wealth in our life.

It is an opportunity to stabilize

housing. It is really nice when you're putting in modifications for people who need accessibility or maybe a person who experiences autism who might need some other environmental modifications, that you don't have to change those. They can stay with the house. It doesn't jeopardize people's benefits. And this is wonderful.

We now have 12 years of information and data with our local project. And on a national level, we're like 18 years of data and information of people owning homes all over the country.

So how do we do this? Through shared appreciation, mortgages for the most part, federal home funds and community development block grant funding and bonds through city programs and nonprofit programs. We are able to access these dollars so that people can purchase a home.

And we always keep the person's -- what their rental payment was, their mortgage became, payment becomes, equal to that. So if it's $600 a month, it's a $600 a month mortgage payment.

And we're finding that there are even more great opportunities now to assist people to purchase because interest rates are low and these grants are shared appreciation mortgages. They get recaptured when the person sells their home. They're available now to assist people with disabilities.

So this is Tony. He's one of our earlier homeowners. He's had this house for six, seven years. People live in modest homes. They don't have a mansion. But they have a wonderful place to live that's clean and safe and theirs. And they can tell you about the control they have over that. And it's their stuff on the walls and such. And they are homeowners and taxpayers.

Tony had a $25,000 shared appreciation from the City of Portland. If he sells the house, that money will go back to the city at zero interest. He may give a little piece of the increased value back to the city, but he will keep the lion's share out of his house. And you have to do some work around that with assets so people keep their benefits.

He also had a Federal Home Loan bank, which is another source of money to help people with mortgage buy-down or second mortgages.

And this is Lisa. This is a picture of her on moving day. She is in the process of buying this home. And a big part of the home ownership thing, what's really nice is people get really involved. We have something called circles of support and helping people create new friendships.

And it is a great way to bring people into people's lives. So the housing provides -- I've got a little note here -- a way for people to connect with community, a way to connect with neighbors and friends.

We have had great success with home ownership. So I am going to try playing this quick little video clip for you. If it doesn't load, we will go over it. It may not load on here. That's okay.

So this is Lisa when she came into her home at first. And what we did is with her building her circle of support, we connected her to some new individuals who were friends that we brought into her life.

She had a Gresham, the City of Gresham, outside of Portland -- she had a shared appreciation mortgage of $33,000. She is getting home funding, by the way.

And so we got these interior decorator friends involved in her life. And this is Rebecca. And they are doing some planning about how they can upgrade the accessibility in her home and how to make it a nicer place to live, not just kind of cream-colored walls and basic things that I might think about but really how to make the house nice and put some nice touches on it.

So here is the house after they have painted and they have brought in color and curtains, they have raised her couch.

They got a couch donated.

And this is all community. All this work was done with $500. She had a small grant from the Portland Rose Festival. And these women that came into her life helped her make this an accessible and beautiful living space, lots of support from local businesses. They included about six or eight local businesses. They create more accessibility for a home and, again, with a small amount of money.

So we are really into helping people connect with the resources that are out there. And, again, I think we can do this by helping people create their own self-determination, their own individual supports in their communities. And all the resources I am mentioning are available in every state in this country.

And these two women on the right are the interior decorators in her life, her new friends. And then the person in the middle is a support facilitator that helps her do her hiring and firing and meeting people and interviewing roommates to live with her in her home.

And Lacy, on the left, does a lot of our work with circles and getting people connected to new community members because, as you hear Charlie say this morning, we know the data shows us that people are less lonely when they live in one or two, that type of thing, smaller numbers, because I believe they get more connected to people.

They share more relationships with the community. And sometimes that's hard when you live with lots of people and if you don't have control over your home, your housing.

One local resource, I have been working in Maryland quite a bit over the last year. We are working with 26 agencies, traditional agencies, helping them figure out individual supports for people.

Melvin is in the middle in the back. He just purchased a home through Habitat for Humanity. He has got a small mortgage, about 450 a month, lives up in Harford County. And so we are starting to see some real success back here locally.

So that is what we do is kind of go into states, meet the people who have the housing resources, bring coalitions together, and start thinking about how do people get individual supports, how do they find roommates to interview.

There is that whole piece around roommates that we have explored, but I think as a general feel we are really just starting to explore because there are people that share rent.

That's what we have all done at some time. We got a place. And we shared the rent. And so there are lots of ways through relationship to move people into people's lives.

And so a lot of our home ownership successes, they just show that they are flexible, they allow for individual circumstances. People own their own homes.

It's not decreasing people's benefits. The person is a taxpayer and community contributor.

We have about a third of the folks that we support who are their own homeowners. And, again, we now have 12, 10, 8 years of data all the way through. And we continue to have new homeowners.

There's also some really recent resources. With all the foreclosure crisis, we're utilizing something called the First Look program. It's a way to get some homes to people that have been foreclosed on, to people with disabilities and other first-time home buyers.

So lots of resources, lots of possibilities. And I think it's the biggest, in a way one of the biggest, crises in front of us because we keep talking about supports.

And I understand supports and self-determination because we have been doing it for the 20 years, but we are not talking about housing. And we need to get ahead. And

I know we are way behind the curve. But, again, some of the resources are out there in the connections.

And I think it is just exciting work to see things happen for people and to go into that generic community, pull out those resources, and have your own rental home or have your own home that you own and, again, or to help families come up with creative options with mixed housing and mixed-income housing so that people with and without disabilities live together.

I think I made the time.

(Applause.)

Mr. Grossman: Well, thank you, Joe and Sheldon.

Questions from the Committee?

Ms. Blackwell: I guess we can ask, Sheldon and Joe, what would your recommendations to the Secretary of Health and Human Services be? We have been asking everyone that. So we have got to put you on the spot, too, guys.

Mr. Wheeler: I'll take a first stab at this. I actually have a quote from Secretary Sebelius on our website. And the comments were given at a university. I can't remember the name or the date, but check out the website.

The quote goes something like this from Secretary Sebelius, "We now know that two of the most effective tools we have to help people recover from mental health and substance abuse are a home and a job."

I have been having these discussions in the Office of Adult Mental Health with the Director of Medicine, the superintendents of the institutions, mental health team leaders, whose world is surrounded in therapeutic modalities. What is the greatest, latest medicine?

And I am waving the housing card. It's the voucher, people. It's the ability to let people have choice, independence, and control over where they live and what services they need to retain.

Thank you.

Mr. Wykowski: And I would second that comment. A few thoughts. One, just working with HUD to continue to look at individuals and having their own vouchers and, again, not group or congregate programs. I think we are making a great shift here. And there is great opportunity in getting people more individualized housing.

And also two other pieces just to continue the message to be to continue to focus on reaching out to the resources that are already out there and do the relationship building with a nonprofit because people are accepting with open arms and they have resources already. So let's make it clear that it's time to community network with what is already existing.

And I think, third, just keep saying that value of quality, not quantity because, again, it's so easy to say we've got 100 people and let's just build 8 at a time or that type of thing. And you need to step back and think "quality" because that is how we create community and create stability and happiness for people over time in their lives.

Mr. Grossman: Any other questions? Jennifer?

Dr. Johnson: Hi. Thank you for your presentation, both presentations. They were very informative and interesting.

Funding is obviously a key component to successful home ownership, but also universal design is an important factor and oftentimes a barrier to home ownership.

And I was just wondering if you could talk a little bit about design as a barrier to home ownership and your experiences with getting around design issues because oftentimes the people who are responsible for design don't quite get and appreciate universal design as a concept and if you have any recommendations around universal design issues.

Mr. Wykowski: Personally we've learned a lot over the last 12 years. The recent homes we have worked on with other nonprofits and partners, we have been able to get to a universal design standard that is very high.

And there are already national studies existing showing that for very little additional money, you can have a home with wider doors, with switches that are available to people that are lower and within reach, easy access hardware for doors, that type of thing.

One of the recent projects we just finished, there were two other nonprofits involved. It was a land trust, which owned the land. And the person has the lease on the home and then the nonprofit builder.

We were able to get to what I feel is like an 80-90 percent level of universal access. And then what we do is we get to know the homeowner. You could make some additional modifications.

For instance, someone might want to have a roll-in shower or they might want to have a tub. They might want to have a certain type of system for a lift and that type of thing. So you can block the walls so that different equipment, whether it's hand bars or the lifts can be put in later and moved, but 80 percent of it can be done up front.

And, again, we're seeing that for very little money and then bringing community partners on the back end if things need to be changed, contractors and such, to donate their time.

Dr. Huang: Hi. Larke Huang, SAMHSA. Thanks again for your terrific presentations.

I have a question first for Sheldon Wheeler. And I can't agree with you more about housing as probably being the most effective treatment in terms of independence.

You mentioned that you had worked on a policy issue in Maine with your housing authorities. Can you say a little bit more about that?

Mr. Wheeler: Sure. Every public

housing authority in the country is governed by an administrative plan. And I'm not sure what the cycle is. It might be every year or it may be every two years. They have to submit this administrative plan to HUD. And contained within the administrative plan is a tenant-selecting process.

And many public housing authorities have foregone the former priorities that HUD used to have to just go on a first come, first served basis. That is sort of in my opinion an easy way out.

What I had done is I had worked with the Maine State Housing Authority, which held about 30 percent of Maine's section 8 vouchers. And I figured if I could influence them, I would get the biggest bang for the buck and my time spent.

So I worked with them for four years through cajoling, pressuring, bringing up words like "Boy, you really wouldn't want a class action suit like we have had in mental health for 20 years," you know, privately. An after four years of pressure, they agreed to modify their administrative plan to include persons with mental illness on a state-funded subsidy as a priority population. And in today's world of closed housing lists, that is our back door to section 8 in Maine.

Mr. Grossman: Marjorie?

Dr. Solomon: Hi. This is Marjorie Solomon from M.I.N.D. This is a question primarily for Joe. And thank you both for wonderful presentations.

One of the really lovely things about the presentation you gave is the wonderful conclusion in the community that the individuals with disabilities in the housing that you helped with achieved.

Do you have any general principles or advice or things that you did that helped facilitate inclusion in the community and got individuals without disabilities involved?

Mr. Wykowski: Because we have larger in the amount of supports we have provided over the years because there was a period when we thought we might just support 25 people and keep it at that, we kind of run the organization in sort of 2 teams, almost like 2 smaller agencies.

But what has really helped -- well, two things. One is breaking off people's time, like Lacy's time and another individual, Emily, to focus on creating these circles of support to connect people because often people aren't connecting to community, especially the people who we have assisted to move out of nursing homes and our state institution, that type of thing.

And sometimes people from families -- there is really some focused time on what people want to do with their lives, where they might want to connect. Coffee shops are big in Portland with all of the rain and such, but people have other hobbies, fishing and such. So connecting around a personal interest and breaking away some time to do that I think has been the main thing that has made us successful.

And then interspersing that in everything we do so the value is community, it is really about that person connecting because I always said getting in the housing in some ways is the easy part, you know.

You know, you move and you get your apartment. You've got the four walls. Okay. So now what are you going to do with the rest of your life? And so focusing and making that the constant message and also breaking away with some of her time around recordkeeping and other requirements for licensing that support agencies or others might have and, again, breaking some of that time free so people create community with people.

And I think it's hard work, but it's exciting work. And the outcomes are just incredible. And, again, it's new for people. And people need those opportunities to connect and have new relationships.

Dr. Solomon: Thank you.

Mr. Grossman: Sheldon and Joe, thank you very much.

(Applause.)

Mr. Grossman: We are going to get set up now for the peer support panel. If Lisa, Jim, and Julie would come up?

Ms. Blackwell: Okay. While they are assembling, I am going to introduce our next panel. This is a panel on peer supports. We have three unique individuals, who will be talking to us about peer supports: Lisa Crabtree, who hails from here in Maryland, the Towson University Center for Adults with ASD; Jim Sinclair, the founder of the Autism Network International; and also Julie LaBerge, who is from the Bonduel School District in Wisconsin, where peer supports have been integrated throughout the elementary, middle, and high school schools.

So, with that, Lisa, I guess you get to start. And thank you.

Dr. Crabtree: I'm an occupational therapist. And I teach occupational therapy at Towson University. But I have been working on the Center for Adults with Autism for the past two and a half years.

In 2008, we got a gift from a family to start something. I was elected. I was doing my research in children, social participation in mental health supports for children on the autism spectrum. And the dean asked me to start a center for adults.

I talked with lots of adults on the spectrum, families, organizations that provided supports for adults. And our first program was supported by a $25,000 grant from Autism Speaks. That got us launched and started. I am going to tell you a little bit about our programs and the purpose of what we are doing.

The first thing I did the first six months was really focus groups and looking at what are the issues for adults that are different than for children.

Some of them are the same: communication issues, having difficulty with social context. Except for adults, it was a little different because at least children had the support systems in a school environment. They had the classroom teacher, and they had a built-in support system.

Once people finished with high school and were in the community, there were no built-in supports. Many of the individuals that I spoke with who had young adults who had finished high school a few years prior had been sitting at home doing nothing or being on the computer, had not had any kind of networking opportunities.

They have difficulty initiating social interactions. It was very difficult for them, and they needed some way to have opportunities to be in a peer environment.

Everybody I talked to wanted to -- this age of 20 to 30 is an opportunity for every young adult to contribute back to the community. They finished school. And every adult on the spectrum that I spoke to wanted to give back, didn't want to be the recipient. And this really developed our programs.

We looked at it as not an opportunity to provide services for adults on the spectrum but to provide an opportunity for them to engage with people their own age and for them to contribute back.

The biggest contribution they have made is by educating our university students about autism. I can give lectures. I can have them do research. I can talk to them in the classroom, but I can't give them the -- or Towson University students give them the understanding of the issues of adults on the spectrum. That needed to come from the adults themselves.

They also needed opportunities to expand their recreation and leisure pursuits. A lot of these young adults were at home on the computer and doing a lot of very isolated interactions. And we wanted to offer them an opportunity to come onto the university campus to be with other people who were their same age.

So when I was doing my research, I

found that the biggest barrier was not anything to do with the individual challenges that people on the autism spectrum had, but it was really the context, the contextual barriers.

This is my metaphor as well. We started. Our first program was on a challenge course. And we did a low-ropes course. And then the last culminating activity is climbing the wall.

But in order to do that, they needed support from below and from above. They needed support from all ends: people helping, pulling from above, and people just supporting it all the way around. The students on the bottom were a mix of students and adults, young adults, on the autism spectrum.

But what we found was that it's the people that mattered. And the individuals, the peers that we worked with had to be educated in some ways about what to do.

They signed up in droves. We put

out a call for volunteers for many of our programs. And we get tons and tons of e-mails from students, "I want to do this," you know, "I'm very interested. I keep hearing about autism on the media. I really don't know what it is. I really want to be involved because I want to learn about autism."

And we tell our adults on the spectrum from the community who are involved in our programs that they are the teachers, "These are students. We need you to be the teachers." And so it is more of an equal partnership.

Research is showing that it's the trained, educated peers that really provide the most support. It's not any particular type of program, but it's the education that the peers receive.

So that we started the Autism Center in 2008 to provide an integrated, interdisciplinary resource center for young adults on the autism spectrum.

And "young" was relative. I

started off thinking that that would be the usual college age, 18 to 25. And then we had people calling us and saying, "Well, I am 28. Can I come?" "Well, I am 32. Can I still come?"

And we have opened our doors. We don't limit anything. We even have had people come to our social groups to say, "I am not autistic, but I really need social help. So can I just come?" We open those doors, too, and we keep it open to anyone who feels like they can benefit from involvement in our programs.

So our main issue is to educate students as peer mentors, as peer supporters. We give them an orientation session in the beginning of the semester. And then we provide ongoing weekly support as the programs go.

Then we also change the social context by changing attitudes and knowledge. What we are really trying to do is educate a group. We have 20,000 students at Towson

University. And my mission is to educate all of them so that when they graduate, they become the workforce in the community, they become the business leaders, they become the people that are going to hire these people on the autism spectrum.

So I am really looking at, really, an investment right now for something long term. We recruited the students through volunteer opportunities, service learning, internships, and course assignments.

We started a post-Baccalaureate certificate in autism and provide graduate students with five courses. And all of those courses I have developed to have a 15 to 20-hour service learning component to them so that they have to give back to the Center for Adults.

We have also connected with Kennedy Krieger, CARD, so that some service learning happens with the transitioning youth. So we've got some transitioning youth programs starting as well. All of our programs incorporate service learning so that they get involved.

These are some of our programs. I will go through them. You can see that we have got lots of peer mentors. We have been collecting data on the changes in knowledge and the changes in attitude of our peer mentors.

We have collected some information about quality of life changes in the participants who are on the autism spectrum. We found the greatest changes happened in our mentors. So I feel like we are really doing our job by changing people's attitudes and knowledge about autism.

We started with a social group because in the first six months, we were doing lots and lots of focus groups, had a focus group with young adults in the spectrum. And at the end of it, I said, "Are there any other questions?"

And somebody said, "Well, when is our next meeting?" So since then we have had monthly social group meetings. They are open to the community. Our first one had six people in it. Our latest one had 38 people. And this is a mix of adults from the community across the spectrum.

I'm not just talking about people who are verbal and who are college students who are on the autism spectrum, but I am talking about people who come with communication devices or people who don't communicate verbally at all but come just to be with peers and participate. It's two hours on a Friday night.

We started the TU crew for our students on the autism spectrum. A couple of -- I have a group every semester of students who organize, develop, and provide access to opportunities on campus.

And what I found, too, was that the students' feedback was "Wow. I never got involved in any of these things on campus until I was researching and finding out what activities the students on the spectrum could do socially on campus." So they have gotten more involved, too.

Our first program was a low-ropes course, which first I was a little nervous about. Well, lots of sensory issues outside, but we had a huge success. We ran it for one year, three sessions, one in the summer, one in the fall, one in the spring, and found that people really came not because they like the outdoor world but came because they wanted to be connected with other people their own age.

We brought it indoors this past year and did indoor rock climbing, too, which was another area. I won't go up on the rock wall, but many of these young adults -- it's a whole trust issue of having somebody hold the ropes and having you go up the wall. And it was a very, very supportive opportunity.

We brought it also inside for a wellness program. We have involved 60 kinesiology students over the past year in various courses. These courses run twice a week for anywhere from 6 to 12 weeks during the semester. We have kinesiology students be peer educators. And the autistic adults are the ones who provide that information about how a customized fitness plan will fit their lifestyle.

We also have adult language and pragmatic skills group run by the speech language pathologist with her students. And they work on language skills, both within the classroom and then also on campus.

We have a women's group because that is my special interest: women on the autism spectrum. When I was doing my research with children, I was really interested in how the girls were very different than the boys. So I brought that to working with some to students, grad students who were supporting young women.

They had a meeting once a month. And then the women on their own decided, "Well, we want to do something more out in the community." And they have been having a monthly dinner club, where they pick a different restaurant in the community and go out and eat.

So our data collection, these are the instruments that we use. There are questionnaires. I am looking for a better quality of life one, and I think that I am going to use the one that was discussed this morning. We're always looking at trying to improve our instruments.

We are finding statistical differences in all of the groups, some on more items than others. When I looked at the differences, I found that the graduate students were not showing as much difference in knowledge because they were the students who had more experience in the autism field. They may have been working or they had more knowledge to begin with.

It was our kinesiology students, who knew nothing about autism. And it's business students and art students and students from all majors on campus. I tried to draw from every major. I am not looking just at the College of Health Professions.

The sign-up for our spring course, I am teaching an undergraduate course in the spring, an honors course, service learning of autism across the life span. And registration closed in 15 minutes. I have a full class. And I have a waiting list of 18 students. So we may open another section.

But when I looked at the students and their majors in that, there are only three who are in the health professions, and there's the rest of the students are from just about every major on campus.

So it is not just the people that are interested, the students that are interested, in providing services or supports. It is everyone on campus. And my feeling is if we can educate people, if the adults on the autism spectrum that participate in our programs can educate our students from all walks of life, from every major, from every interest, I think that we are going to create a more supportive community.

The areas of knowledge change were knowledge about autistic characteristics, strategies, some goal setting, how to just communicate and work with people on the autism spectrum.

Attitudes changed in all groups. They didn't change in the TU crew, which was college students, because I looked at that group. That was a group of family study students who we evaluated.

And family study students did not want to admit in the beginning that they had any attitudes at all about anybody with disabilities. That was their background, their training. They were also seniors about to graduate. And so they had had a lot of education about having positive attitudes.

These are the areas, all different areas, of attitudes. Whether it was people with disabilities should be employed or they should get married, it's a standardized measurement tool that we used. And it impacted attitudes in every area.

For the participants, we saw some changes in time management skills, emotional control, social competence throughout several of the programs. But the changes weren't as great as they were for the mentors.

Some feedback. We're looking at feedback from the students, the Towson University students. They felt like they had some tools, that they learned from each other.

And I especially liked this quote because I felt like what we were trying to promote was an equal interaction between peers, not a service towards people on the spectrum as much. This person felt like they could be an advocate, they and the skills, they had the tools now to then when they graduated, to be a support for people in the community.

And they were seeing that what was previously seen as something very odd or strange has now "Oh, now I understand because -- not because I told them but because they worked in supportive pairs with these individuals." And we did some really fun activities. We weren't really directed towards lessons, but we were just giving them the experiences of interacting together.

From the participants, they enjoyed the activities. And they, the participants, also said, "I enjoyed teaching the mentors. I enjoy being in that empowered position where I was the teacher and the students were the students, instead of always being on the receiving ends of things."

And they felt it was really important to have these group experiences, even though for many of them it was very threatening in the beginning. Many people were sort of dragged there by the parents and said, "You need to do this." And the first session would be sort of looking around. But after they got to know the students and they were working together on some really fun activities, that changed completely.

Many people -- and I want to emphasize that we were not focused on any one type of person on the autism spectrum. We opened it up. Anybody that wants to attend we make accommodations and we educate and provide support as much as possible. And we haven't had any issues at all.

Some individuals communicate -- there was one example of a kinesiology student that was working as a personal training with somebody nonverbal. And after two sessions, I asked him how he was doing. And he said, "You know, it's really great."

I can tell when he's getting tired or he wants to change equipment because he sings a lot. He just hums to himself. And when the humming goes, you know, it changes a little bit in this patient or that patient.

Now, this was a student who had no training at all in how to communicate with a person on the autism spectrum. But he was communicating with his partner in this. And he really understood a lot about how they could communicate during those activities.

From parents, they felt like, you know, he was actually talking to somebody his own age. You know, he doesn't do that. He doesn't talk to other people. But he did immediately go and start talking and working with his mentor.

The last quote is that he -- you know, when he got in the car, he said he had fun. This was a student who they -- it was a rock-climbing activity. And all they did the first session was try on the equipment and learn the safety rules.

And when he got in the car and he said it was fun, the fun part, the engagement came from just being accepted. It was being in an atmosphere where he could be with his friends, be with peers his own age, and do things with people that were on a college campus. You know, it wasn't a contrived situation.

So I think that we can all have that opportunity to provide an environment that is accepting and open. It doesn't cost a lot of money. We charge a little bit to cover our costs of having a faculty supervisor for all of these programs for the training and the education parts.

But our students are free. And I think that we're not tapping into this resource. We had 20,000 students who will work for free. That is a huge amount of capital that we've got that we're not tapping into I don't think as much as we could be. Every college campus could be doing this for the communities that they're in. And I think that we need to think about how to use that resource.

And there is my contact information. So thank you.

(Applause.)

Mr. Sinclair: I'm Jim Sinclair. I have been the Coordinator of Autism Network International since it was founded in 1992. And as part of being Autism Network International's Coordinator, I have also been managing Autreat since the first Autreat in

1996.

This is an annual retreat run by and for autistic people. To my knowledge, it is the first such event ever, but it has now inspired some other groups to follow suit. And some other groups of autistic people have started organizing similar events, which brings me to an incident that happened about five years ago at an event modeled after Autreat that I was asked to consult with the organizers.

The organizers were a group of autistic people who wanted to do something similar, did not have the experience, were I think scared half to death about various things that could go wrong. And so they brought me in to consult with them and also because, in addition to being a self-advocate, I am also a qualified counselor. They felt better having me around just in case anything went wrong.

Well, everything went fine until the last day of the event, when I believe during the last workshop a participant suddenly burst into tears and ran out of the room sobbing.

And I am the counselor on duty. And I went out. I waited a while to see what was going to happen because generally autistic etiquette indicates when in doubt, leave people alone.

I waited to see if she would go to her room or go off to be some place alone. When she continued to sob and wail in the hallway right outside the presentation room, I figured she probably did not want to be left alone.

I went out in the hall and observed that she had her green badge showing. This is another autistic cultural artifact. This is an interaction signal badge. And the green means, "I want to interact, and I am having trouble initiating. Please help."

She could have been wearing that before she broke down. I don't know. But I figured sitting in the hallway when she had been able to get herself out of the room but no further and wearing a green badge, probably wants to be interacted with.

So I sat down there on the floor next to her, and I asked her how I could help. She said she felt useless, she wished she were dead, and she wanted to kill herself.

This is not the kind of thing a counselor likes to hear. So my first reaction to "I would like to kill myself" was "Please don't," then tried to encourage her to tell me what was wrong. As we're sitting there in the hall outside of the room where the presentation is going on and other autistic people are coming by see us sitting there in the hall, see her crying, stopped and asked what is going on and started trying to reassure her and to encourage her and to help her.

We ended up with about five or six autistic people sitting in the hall, blocking the hallway. A neurotypical professional, who was at the event to hear more about autism as she was trying to weave her way through bodies sitting on the floor blocking the hall, said, "You folks sure are giving the lie to all of those people who say that autistic people are incapable of empathy."

I think the neatest thing about that entire situation was the one autistic person who had been going around through the whole event holding a visual stim toy in front of her eyes and not looking at anybody. She walked by and, without a word, handed the stim toy to the person who was crying.

This would never have happened -- well, the stim toy reminded me that the person who was crying is actually more musically inclined and visually inclined.

So I ran and got an MP-3 player and played a song for her called "Butterflies" -- I don't know how many people have ever heard Connie Deming's "Butterflies" -- explained to her that Connie's son David, who the song is about, can't speak, can't do many of the things that this woman is able to do, requires a lot of support, and his mother is able to perceive that he is a butterfly. Her response to that was "We are all butterflies."

Okay. A couple of things about that illustrate autistic peer support. First of all, this would not have happened if it had been a neurotypical counselor who reacted because an NT counselor would have seen the woman sitting on the floor crying and said, "Let's go someplace more private."

We wouldn't have had the counselor and the crying person sitting in the hall trying to figure out what is going on. Therefore, we wouldn't have had the five or six other autistic people noticing a peer in distress and coming to help.

That happened because the counselor was autistic and thought only about what is going on right now in front of me and not about "Let's go somewhere else."

The other interesting thing about the counselor being autistic is that I woke up that morning without speech. The previous day I had given two presentations, led an interactive discussion, had a meeting with a person who wanted to meet with me individually, and been up until 2:00 o'clock in the morning attending a meeting of the organizers and consulting with them. I woke up that morning, and my speech didn't work.

So I was communicating with this person in crisis by writing, which becomes significant. I was writing notes on a notepad. She was answering me with speech.

When I wrote on my notepad that David's mother recognized that David is a butterfly, instead of answering me with speech, she took my pad and my pen, and she wrote, "We are all butterflies."

That was an autistic peer connection that happened because not only the person receiving support but the person providing the support was autistic. So that's what I'm here to talk about is peer support, meaning autistic-to-autistic support.

The first thing when you are talking about support is you have to ask whether the person wants support because very often autistic people are perceived to be in need of support because we're isolating ourselves and sitting in our own space and not coming out. It may be because we want to be sitting in our own space and not coming out. It might be because we want a refuge from all of the demands that the NT world places on us because we don't want people intruding.

At the same time, there is a need for support in the form of decreased structure, boredom, loneliness, difficulty managing. Autism is a disability that very strongly involves executive functioning skills. If you are autistic and you don't have anybody involved with you, you are very likely living in chaos.

So next slide, please. Do I have the flipper? Okay. Being autistic among NTs. And I divided these into two columns: those that are perceived as negative and those that are perceived as positive. Most of these are actually, as far as I am concerned, all negative.

Being confused, overwhelmed, isolated, excluded, or devalued are things that autistic people will generally experience as negative things at the time they are happening.

On the other hand, there are compensations: being considered special, being admired, just for getting out of bed in the morning, for getting dressed, for being able to string together a coherent sentence. For doing things that typical people are expected to do as a matter of course, we get admired for doing. We get considered heroic for having a job.

Being cared for, being allowed greater latitude. It consistently amazes me when I read -- I'm on a listserv of disabled student service professionals in higher education, and I am consistently reading about autistic or Asperger's students who come to college never having learned basic concepts of self-control, have been allowed to get away with things because it has been perceived that "They can't help it. They can't learn to control themselves." And so in order to make accommodations for autism, we have to let autistic people get away with really sometimes incredibly inappropriate behavior.

I'm not talking about being weird. I'm talking about sexual harassment of classmates and other things that the real world is just not going to let you get away with.

So all of these may be perceived as positive aspects of being autistic at the time they are happening by the person that they are happening to but I think in the long run are not positive.

The one thing that really is undeniable is that if you are autistic and around neurotypicals, you probably have people around you who are less confused and overwhelmed than you are and, therefore, are more able to help you if you need help.

Being among autistic peers also has its benefits and challenges. It can be a huge leap of insight to realize "There are other people like me. I am not the only one."

At the same time people come sometimes to an event like Autreat expecting everybody will be like them and then are disoriented, disappointed. One person had a meltdown the first time she came to Autreat because there was nobody else that was just like her. And she thought, "I can't even get being autistic right. If I am not like these other autistic people, what am I?"

You get accepted for who you are, even if you are weird. At the same time you have to accept other people, who may be weird in different ways than you are weird. And that can be difficult for some people to deal with.

I expected when ANI first started and we first started having people get together, I remember one time there were two people who had just joined our little micro, mini network at the time who were both at the time doctoral students in universities.

And we were meeting at the home of a family that had a non-verbal teenager with a diagnosis at that time of profound intellectual disability. Well, at the time it was profound mental retardation.

I thought, how are these doctoral students going to react to their first encounter with other autistic people to being around this person. They reacted just fine. At one point the teenager, the non-verbal teenager, plopped herself down on one of the Ph.D. students' laps. And he just sat there smiling.

But it can be a shock for some people, particularly people who have had their ego and their self-esteem built up all their lives thinking, "Well, I am not like those low-functioning people. I am special."

There is a presumption of ability among autistic peers. So people start thinking, "Well, maybe I am not helpless," especially when I see other people that are like me that aren't helpless that are capable that are competent.

It is the issue when I was an intern in an elementary school, I had an autistic client. I had every autistic client in the school. The kid wanted to sit in my wheelchair one time.

I can walk short distances. I don't need to be in the wheelchair. I can especially walk while holding onto the wheelchair, which I would have had to do with this kid to keep him from doing wheelies and breaking his neck and needing his own wheelchair.

So I let him sit in the wheelchair and roll down the hall to the office, where we were having our meeting. And I held onto the back of the chair and walked behind him. And as he wheeled into the office, he called out to the secretaries, "Look at me. I'm a counselor" because you know what? The counselor is cool. At least I am a cool counselor. I don't think all counselors are cool, but I am.

And when the person who is cool is also autistic, I guarantee you the peer mentoring program that I ran for the elementary school kid was very different from the peer mentoring program that a neurotypical counselor would run for elementary school kids.

At the same time there is a presumption of ability. People may not notice when you need help. You may have to speak up. You may have to say what you need. And then once you say it, you may find that other people don't have the spare resources to give it to you.

We had this happen on occasion at Autreat that people show up expecting that they can just ask for whatever they need without having made prior arrangements to get it and other people are going to be available to help them. And it just doesn't happen.

And I have had to explain to a couple of people if you need this level of support, you need to make your own arrangements to bring a support person. What does that do? It gives the person the responsibility for their own support needs. You can't just be helpless and expect that everybody around you is going to take care of you.

Having difficulties acknowledged. We have a lot of people that are considered very high-functioning. I'll talk a little bit more about what that means later on.

But people generally perceive that if they have to do it all, if they are high-functioning, they are not allowed to ask for help. They don't need help. They just have to try harder and work harder and push themselves harder.

And then they find out they are allowed to ask for help and they find out, you know what, they can do a whole lot of things that they previously never had the energy to attempt because they weren't getting the support that they now know how to ask for.

And especially the idea of reciprocity, which is where I am going with the rest of this presentation, people aren't just receiving help. They can help other people, too. That can be a life-changing experience for a person who has always perceived themselves as being helpless, needy, incapable, and dependent on others.

I gave a training to the organizers of another autistic-run event on peer support and, well, mostly crisis prevention and crisis intervention if a crisis happened. And one of the organizers said afterwards, "I had to restrain myself from thanking another participant who was having a problem because it made me feel so good to be able to help her." This is somebody who is used to always being the one in need of help.

Okay. Next one. People ask me sometimes, "Well, how can we set this up for our clients?" Well, if the person asking that question is not autistic, the answer is you can't.

The difference between autistic spaces versus places for autistics is who designed it, who decides what is needed, who makes the decisions and rules, who does what needs doing, who is empowered. If you are providing something for a group of people who are not you, you are not empowering those people. You are keeping them dependent on you. So the first thing about autistic peer support is it has to be done by autistic people. You can't do it for us.

Autistic -- and very quickly here because I have a whole 30-page article and a link to it. You can read the whole thing. Could you flip it, please?

Autistic peer interactions take into account the needs of autistics, both the autistic people that are in need of support and the autistic people that are providing the support, who can be the same people at different times and even at different points in the same interaction.

So here are just some characteristics about what those differences may be. When the mentor or the supporter is also autistic, the dynamics of the relationship take this into account. As in the example that I started with, you know, when the counselor is autistic, you might be sitting on the floor in the hallway.

I can't tell you how many counseling sessions during my internship in an elementary school I did underneath tables because that is where the kid was. I didn't require the kid to come out from under the table and sit in a chair. I went under the table with him.

Then I have -- and I don't have time. People are going to get this handout, right, so they can look at the quotes. Because what I want to go onto -- and it's not up there -- the qualifications for being autistic peer supporters. Just being autistic is not enough.

I should probably keep a file, instead of throwing them in the recycle bin, but I routinely get letters and e-mails from people saying, "I am autistic, and I am giving a talk" or "I am writing a book" or "I am doing" this or that and "I can help people understand their autistic kids."

Interestingly, they don't say, "I can help other autistic people" because that is not where the attention is. That is not where the money is. That is not where the glory is.

"I can help parents understand their kids." Okay. What are your qualifications to help them? "I'm autistic. I got diagnosed four months ago."

I don't tend to get these kinds of letters from people who got diagnosed in childhood. I think those people have a clearer idea of the fact that autistic people aren't all alike. But people who get diagnosed later in life and, all of a sudden, people are willing to listen to them and to pay attention to them and to admire them and to consider them heroic and special, it is not enough to just be autistic. That doesn't make you an expert in other autistic people.

As a counselor, some of the kids that I have made the most effective connections with in terms of outcome in increased self-control and in changing behavior and competent social skills have been kids who were the most unlike how I was when I was a child.

When I was a child, I was effectively non-verbal. I could use echolalia very effectively, but I could not string together words that I had not heard before.

I was not social at all. I was totally withdrawn to the point of actually becoming catatonic if anybody approached me. I was unreachable. I have worked with kids who are constantly trying to engage inappropriately, violating boundaries, talking nonstop, social to the point of being a danger to themselves because of the way they approach total strangers, total opposite of the way I was when I was a kid.

Those were the kids that I made a difference to. The one kid I can think of that was the most like me when I was a child is one of the ones I had the most trouble reaching because that child, like me as a child, had no interest in being reached. Maybe somebody that was more intrusive would have been able to get that child's attention better than I did.

So being autistic isn't enough. Autistic providers need to be screened. You can't assume that all autistic people that are interested in helping other autistic people have positive motivations for that. We need to be screened. We need to be trained. And we need to be supervised to the same standards as other providers.

Autistic people should not be allowed a free pass to go and do whatever we want just because we are autistic because a lot of damage can be done that way. It's like putting any other untrained person in a position of trust. Don't do it.

There is no ceiling. Autistic people can be very highly educated professionals. I am sitting here as a certified rehabilitation counselor. Every year before Autreat, I do staff training for the Autreat child care staff with an autistic occupational therapist.

At Autreat this year alone -- and in the past, we have had other professionals, but this year we have had autistic people -- well, let me go on to my next point first, which is that there is no floor. You don't have to be capable of going to college and going to graduate school and getting an advanced degree to be able to help other autistic peers.

People can be paid service providers, volunteer peer helpers, or mentors without requiring advanced academic education. So the examples from Autreat 2010 alone, this one year at Autreat, we had autistic people who were occupational therapists, counselors, teachers, teaching assistant, personal care attendant, parents, and siblings. You can't rule those people out as peer helpers or mentors.

There are many autistic people who are parents of other autistic people or who are siblings of other autistic people. We had a family here this year that the mom has adopted several autistic children. So we have a bunch of autistic young people that all have autistic peers.

We also had young people interested in getting jobs and training as a school bus monitor and a children's librarian. Those are all roles where people will come in contact with and be able to help other people, both autistic people and non-autistic people. And they require varying degrees of academic education.

So what are the barriers to peer support being effective? The first one is a presumption of inability. There is a presumption that autistic people can't be helpful to other people, that we must always be the recipient, the beneficiaries of services and assistance.

So there is a presumption that we are not capable of going to school and getting degrees or getting training or having a job. There is a presumption that we cannot be helpful to anyone else, we just need to be helped ourselves. There is this all or nothing dichotomy. You are either high-functioning or you are low-functioning.

Do you know the difference between being a high-functioning autistic and being a low-functioning autistic? If you are labeled "low-functioning," it means you are not allowed opportunities because it is presumed that you can't do things. If you are considered high-functioning, you are not given the support you need to access the opportunities because it is considered that you don't need supports, all or nothing.

That is a major barrier because a

lot of us are not in a position to be able to help other people because we are not getting the support that we require ourselves.

Lack of available peer support training. If you have a physical disability, if you are blind, if you are deaf, you can go to an agency that serves people like you and is run by people like you. And you can get trained to help other people like you.

There is not a lot of training out there for autistic people to be peer supporters. I've given some of that training. And, again, you know, one of the feedback was the person who had to restrain herself from thanking another peer from having a problem. It's not out there.

And I have gone to my local Center for Independent Living and asked for peer support training. And they didn't have anything that was relevant to autism other than, you know, the basics that are relevant to everything: confidentiality and unconditional positive regard and that stuff.

There is inadequate support for the necessary education or training. Do you know what it took me to get a Master's degree? I mean, first what it took me to get a Bachelor's degree, my first vocational rehabilitation counselor sent me to a psychologist for testing, came back and said, "You have a very high IQ," which I kind of sort of was already aware of because I had gone to a high school for gifted children and left at 15 to start college, where I was maintaining a straight A average. Therefore, she was going to send me to a two-year program to get a technical degree.

I said, "I want to get a degree in psychology."

"Well, you can't do anything with a degree, Bachelor's, in psychology."

I said, "I know. That is why I am going to go to graduate school."

Well, the graduate school I was in was in a whole other state. And they wanted to send me to get a job at McDonald's.

So there is inadequate support for the necessary education and training, even when such education or training is available. There are inadequate vocational services.

I have a degree. I don't have a job. Why don't I have a job? Because vocational rehabilitation services are not designed for people like me.

So I know the question is going to be what recommendations. Incorporate autistic people and autism services into the Center for Independent Living model.

I have tried myself over the years. And I have tried to refer other people that I am trying to assist to Centers for Independent Living. And there is very rarely anything there.

I called one Center for Independent Living earlier this year and asked if they had services for a client, consulting client, who needed independent living skills training, which they offered to people with other kinds of disabilities. And they referred me to the

State Agency for Developmental Disabilities, which is not a peer support program. It's a traditional program where people who aren't disabled decide what people who are disabled need.

So autistic people and autism-specific services need to be incorporated into existing peer support and peer training programs.

There needs to be more meaningful independent living skills training for autistic people. I have heard a lot of people talk about the gap between the need and the available staff. Well, if there were adequate independent living skill services, there would be less need for support. There just isn't.

People that are considered low-functioning aren't given support services for independent living because they are considered incapable of being independent. And people that are considered high-functioning aren't given independent living skills training because we are not considered to need it.

I am just one of many autistic adults who crashed and burned when they moved out of their parents' home because I graduated from college with a straight A average, but nobody ever taught me how to live on my own.

Autistic mentors can train other people in those skills, sometimes better than non-autistic mentors for the same reason that applies to any other disability. Those of us who have figured out the solution to a situation, we have been there.

Support existing autistic peer support networks in terms of where you direct your funding. Instead of starting to reinvent the wheel by people who are not autistic, look at what autistic people are already doing for ourselves and direct some funding and some support there.

Develop training for autistic peer support similar to the peer support training that is already provided at Centers for Independent Living for other disabilities.

And, again, experienced autistic providers can provide that training. I have done it. Sue Golubock, who is an occupational therapist, has done it.

I am training. I think I tried training this year. And it's going to be next year before we find out how it works. But I recruited a new director for the Autry Child Care Program, who just graduated from college with a degree in education and is autistic and is a sibling of other autistic people. So he has been through the training that Sue and I gave once. And I am going to see next year how he does at training other people.

Encourage and support interested autistic students to pursue career goals in service and support, instead of sending them to work at McDonald's or to get a technical degree.

I know a young man who is 18 years old. I met him when he was 11. I have watched him grow up. He has just started college. And when I saw him last summer, he couldn't wait to go to college and to graduate from college. He wants to be a special education teacher.

When I was his age and I wanted to be a psychologist, I was told I couldn't do that. He is going to a college that is encouraging him and supporting him to pursue that goal.

So he is 18. I don't know what the current average is on the number of times college students change their majors before they graduate. He may not become a special education teacher, but if he persists in wanting to become a special education teacher, he should have the support he needs to do that because at 18 years old, he is using vocabulary that I have to teach professionals that haven't been there in terms of the research on autism, the classification of disability, the ways that you provide support.

So there should be encouragement. There should be support. There may need to be scholarships. One of the problems that autistic students at university level may face is because of the executive functioning and the difficulty with shifting mental gears, we may need as accommodations reduced course load, which means we become ineligible for scholarships that require full-time attendance. We may not be able to go to school and hold down a part-time job at the same time. So there may need to be scholarship assistance specific for autistic people to be able to overcome those barriers.

Improve home and community-based services and vocational rehabilitation services to increase the pool of autistic people who are in a position to help others because, again, if I can't get a job, if I cannot consistently get myself out of the house and readied for work on time, organized, remembering to bring the things that I have to bring, remembering to follow up on the things that I was supposed to do yesterday, I can't have a job.

If I don't have the support in the

workplace that a job coach provides and then leaves -- but if the disability is autism, the need for that job coach is not going to go away -- I can't maintain a job.

There are a lot of autistic people out there who could be working but who aren't or who are working unsuccessfully and racking up a string of unsuccessful job experiences and job losses because the support isn't there.

So, to sum it all up, invest in autistic capability. Stop pouring a lot of money into research to prevent future autistic people from existing, and start putting out money into helping autistic people who are already here and into helping us make things better for the coming generations.

Thank you.

(Applause.)

Ms. LaBerge: Good afternoon. Thank you so much for the opportunity to be here today speaking in front of you about a topic that I think is very, very important as we talk about working with children with autism and helping them develop peer relationships and improve their social outcomes.

We have been working in the Bonduel School District for the last couple of years with the National Professional Development Center on autism spectrum disorders.

Wisconsin was one of the states that was in the first cohort. There were three states chosen in the first cohort of that project. And we were involved with trying to organize a system to implement evidence-based practices within the schools.

And so Bonduel was invited to participate as a model site school of a real school. We have about 880 students in our districts. And we were chosen to try to implement evidence-based practices. So I will walk you through that process as we go here, but after our first year, then we were invited to participate in the second year of that project as well. So then we made this district-wide and included our elementary and our high schools.

We are continuing the implementation of peer supports this year as well. And we have got a lot going on. So I also failed to put on my identifying information on your slides, but I will just comment that I am also the mother of identical twins, who are 13 years old, going to be 14 this weekend, and they both have autism. And also we also have a daughter, who is nine years old, and she is typically developing.

So our boys were involved in this process. And it is really quite interesting to hear their perspectives as a parent and also an educator.

So I am just going to give you a history of where we were at with this project when we first began to where we are at today. So in Spring of 2008, we worked with the staff at the Waisman Center out of UW-Madison. And a bunch of folks came up and visited with us. And these are our identified technical assistants who are going to help us implement these evidence-based practices within our schools.

We introduced them to several different staff members within our school and kind of figured out what the scope of the project would be.

Now, in the Summer of 2008, seven staff members from our school district attended the summer institute down in Madison and learned more about the evidence-based practices and the purpose of this project.

So in the Fall of 2008, the folks from the National Professional Development Center and Autism Spectrum Disorders visited our middle school.

And then they gathered data using the autism program environment rating scale, the APERS, and trained our staff to conduct goal attainment scaling for three of our students.

And I have an example of what the goal attainment scales look like, but, really, what it was is we identified the most important goals that we wanted students to work on and put them into a different type of perspective.

So, as a special education director, we're developing IAP goals all the time. Sometimes they are a little bit broad in their scope. This really identifies what the main purposes are. So this is one about engaging in functional communication.

We identify the goal, identify where we want to be here, after we implement this evidence-based practice and what would the outcomes be if we exceeded what we are expecting. So it was kind of a neat process to look through that. And we are continuing to use that within our schools today.

In the Fall of 2008, the Bonduel autism team received results from that APERS, the observations that took place, and determined what evidence-based practices that we were going to implement.

So what we found was that the

students at the middle school, the target students that we had chosen, they all had something in common. They were all considered high-functioning, if you will. But they all struggled with social relationships. And what they noticed in the observations is there wasn't a lot of initiations with peers with autism to those without autism and vice versa.

So we chose peer-mediated instruction and intervention. And we looked at how we could put together a system to increase those social connections.

We took data. And we just created a data sheet just to gather data, paraprofessionals and teachers. And we tried to make it as unassuming as possible. Rather than having people go into the classroom and make a big deal about taking data, we just did it within.

And so we looked at the classroom between classes, the lunchroom, et cetera, the amount of time. We looked at the number of interactions with students without autism and the number of interactions with students with autism.

And then we expanded it a little bit just by asking the folks who were taking data to identify if when the students with autism were communicating were they on topic and just to kind of give us a little bit more of a feel of what that looks like, those interactions.

So then, based on all of that information, we said okay. We have to follow this implementation checklist, which is part of the process of the evidence-based practices.

And so we had this implementation checklist that we were walking through. And we said okay. The first thing we need to do is identify the peers. And so we asked teachers, you know, what students are nice, kind, caring, compassionate kids in your classrooms. This is pretty much the requirement. It doesn't need to be the most intellectually gifted, doesn't need to be the best at anything, just has to be nice and compassionate.

So we then came up with a name because we said okay. We're going to develop this program. We need to give it a name. So we called it Power PALS. And the PALS part meant Peers Assisting, Leading, and supporting.

Then we gave all of the students who were nominated a copy of this implementation and told them that "You are invited because of your ability to serve as a leader. Okay?" -- these kids had that ability -- "to understand the importance of helping others feel like they belong, to recognize strengths in others, to be kind to others, to understand the importance of helping others."

And ultimately we wanted these kids to know that they have been recognized because of the great qualities that they have as people. All right?

And then this was the big

incentive. We offered them a lunch tray that included pizza and pop, soda. And that was really exciting. You know, middle school kids really get excited about food. So that was really neat.

And we also told them that they needed to check in with their PMII trainers, which then we would explain who those folks are, and then that they would serve as a positive peer support for the students they would be assigned to and then help teach and lead those students to learn social skills needed to fit in within our social system in our school.

So then we created consent forms. And ultimately we did this partly because we were involved in this national project and we had to have consents but also because we knew that we were going to be working with children without disabilities and we needed to talk to the parents of the kids who have disabilities about the possibility of sharing information and making sure that that was okay.

So all of the students received consent letters and just talked about -- again, this went home to the parents of these non-disabled peers and talked to the parents about how great their kids are and how we want their help. And so ultimately the kids, every one of them who was invited, participated in the project and indicated that through their signature as well as the parent's signature.

So we developed three groups total at that time. There were two sixth grade groups and one seventh grade group. The groups included 19 typically developing peers total and 4 students with autism spectrum disorders.

Now, the PMII groups, we did the social awareness training in three different group situations. We used the Sixth Sense Curriculum by Carol Gray.

And what I did is I took that curriculum and made it into a PowerPoint. And we walked through this PowerPoint with all of the students so we could do that training. We talked about the five senses. We talked about what information do you gather? What do you think you would be like if you struggled with any one of those senses?

We do a little bit of role playing, too. And it's kind of fun because the kids get to experience what it is like if they can't get something when people are gesturing to them and so forth. And we talk about just what it would be like if we couldn't understand and so forth.

We talk about how typically developed people just know what is going on around them. They just perceive things a little bit differently. So we do another role-playing type of activity to have them experience some things, too.

We talk about emotions, facial expressions, those types of things that might be difficult. We talk about, you know, making good guesses. We can do that, but it might be difficult for others to figure out what people are thinking or feeling.

And then we talk about this being our sixth sense to be able to perceive what other people are thinking or feeling. And then we talk about what would be hard about life if you couldn't figure that out.

So the kids kind of get a lot of experience. And, again, this took place during a lunch period. But this is where it became a little bit more focused on the individual students.

We started talking about the actual student that they would be supporting. You know, "Have you noticed a time that Brandon has had a hard time talking to others? And what happened?" And then they would go on and on and on because kids do that.

And then we had ideas. And I asked them. We had a white board up. And we asked them for their ideas, "How could they help a student?"; things such as "I could e-mail," "I could call," "I could use Facebook," all these things, social networking, that kids are doing now. They were thinking of ways to bring the kids in and have them be part of that, too.

So it was kind of a fun training for all the three groups. And we just tried to make them more aware because we knew that we needed to be aware of what their mission was when we got this going.

So a regular education teacher was participating on this team. And she was one of the trainers, speech and language therapists and myself, I had a group.

And we instructed and coached those non-disabled peers for about six weeks or so, where we would send them out with missions to support. If they got stuck, they would come back and report to us what happened and what went wrong and so forth. So we were just constantly coaching them in that process.

And then in March of 2009, we decided that we needed to make this bigger, we needed to develop those relationships to be stronger. And we invited the kids with autism to join the groups. And this was maybe a little outside of that implementation checklist.

We had done all of the things according to the checklist and everything. But now we needed to build the relationship. We needed to have these kids interact with one another. So we worked on games, social, different activities, role-playing, and so forth, until the end of the school year.

And then we went on a group outing to a baseball game in our community, the Timber Rattlers up in Appleton. And you can see here. I mean, these are kids with and without autism interacting with each other in a very fun, social way. It was really a good time.

So the parent feedback from that first year was one parent said, "My son is more happy when he comes home at night. He's been talking about the Power PALS program and even talked about having new friends."

His mom said he has really seen a difference or she has seen a difference in that he probably feels more comfortable. And she wondered if kids were sticking up for him at school. And I told her that there were kids sticking up for him at school because in the previous session with my group, the students who I was working with had come out of gym class and he was really, really excited one day, went into the locker room and had a hard time settling down.

And one of these peer supports was in there. A bunch of other kids started making fun of the target, the student with autism. And the peer support said, "Hey, guys, knock it off. He's just like us. He could be just like us. And don't make fun of him." So immediately that stopped. So that was a really neat outcome.

Another parent indicated that she believed that her daughter was trying to be more like the other girls. And in this case, the student -- this girl had a lot of interactions with boys, but her goal, the mom's goal, was for her to interact more with girls.

And so now she wanted to be more like the other girls. And she stated to her that her daughter initiated laughing and joking more at home and said that she wanted to do different things, like stopping and getting hot chocolate for catechism, like the other girls did. And she thought that her daughter was more aware of her appearance and wanted to interact with other girls after that group had started.

So a teacher then provided some feedback. She was working on a PowerPoint with one of the students and said, "I think it's really good. And I know it's because of the connections that he's making with the PALS group. Those are the kids that are teaming with him. So now it is extending into the classrooms as well. And he seeks them out when he is stuck. And it's a much higher caliber of work than what you first observed at the beginning of the school year."

So now that the student has some

peer supports, he was going to them and asking for input. And they were supporting him. And everything was better. The outcomes were better all around.

And then the teacher aide, who was in that classroom supporting the class as a whole, said, "I agree he did an awesome job" and was very concerned about what it looked like. He also did a nice job asking for help from peers, instead of the adults in the room. That was a key thing for us.

That's what our mission is, to get them to ask for help from peers, rather than going to the adults all the time. Of course, you need to go to adults at times but not all the time, so really positive stuff.

And then one of the students -- I'm going to actually show this in the video later, but this is a quote from one of the students. And it was just really neat. And the student continues to benefit.

So the pre and post-intervention data, this is for McKenzie, one of the girls on the project. And her peer interactions before, she had like one interaction. And then McKenzie's initiations were about three.

And then after, her peer interactions increased to over four and McKenzie's initiations were four as well. The most important piece that is highlighted here is that McKenzie interacted or extended her initiations to a group of girls; whereas, before, that was not happening. She was interacting more with boys. And so her mom's goals were being addressed there as well.

And then Brandon, you can see his before and after results, the peer before initiations were two or so. And then after, there were quite a few more. And then his initiations also improved. But his also took place during recess and before school; whereas, before he kind of got lost during those times. He didn't quite know what to do in the hallways and so forth. So his really improved.

And then this was kind of a

surprise outcome. In that summer after the first year of the project, the students, they actually initiated -- one of the students with autism initiated a movie night. And he called one of his trainers and said, you know, "Mrs. Sorley, I would like to organize a movie night. Can we all go to the movies together?"

And then he ended up calling all of the kids in his group and all of the other kids called their kids in their groups. And so 21 people showed up up at the movie theatre and had an outing directed by a student with autism, which is really neat.

And then we moved into year two. We attended the summer institute. There were 11 of us that attended this institute in Madison. And we expanded to the elementary and the high schools. And we again then looked at three target students at the elementary, three target students at the high school because that was part of that National Professional Development Center requirements.

And we started two new groups of

PMII groups because there is a social need again, you know. And we also looked at other evidence-based practices as well, but today we are focusing on the PMII.

So at the elementary, we took that same PowerPoint. And we just modified it a little bit and just made it look a little bit more kid-friendly for the younger kids. And it was really kind of neat because the kids really enjoyed this training as well, and they really liked the pizza.

So we started a group also for a student not identified with autism, a student who has a different disability, more of an emotional/behavioral disability, but needed social supports. And so that was really important for him because kids perceived him as being a danger. And they were afraid of him because of his behaviors.

So now he has peers that will actually be able to interact with him and that he can trust. So there was a nice outcome with both of those situations that carried over as well into this year.

And then at the high school, we also looked at three target students there and started a group for a student up at the high school who, again, his parents had indicated that he hadn't had a lot of interactions with peers outside of school. And that has worked out really well.

What we did at the high school, though, is we changed the title from Power PALS to P.O.P.S. We call it the Power of Peer Supports.

What we did with this is we had six students without autism supporting the one student with autism. This year we are adding another student with autism to that group as well.

But the target student with autism now talks about having friends at school. And he didn't have that before. So his mom is thrilled about this. He seems to enjoy attending school more.

And this is one of my favorite

outcomes so far, is that this student actually -- well, this group. They decided at the end of the year that they wanted to work independently of the adults and they wanted to run this group on their own.

So about two weeks into the school year this year, I had one of the kids come into my office and said, "Mrs. LaBerge, where is that game? Where is that game? I need the imaginative game."

And I said, "Well, it's in the closet. Go get it." I said, "What are you doing?"

And she said, "We want a group. We've got to start it" on her own.

And I'm like "Good for you guys." I didn't even have a chance to check in with them yet. So I was really excited about that.

And they meet every single week religiously, and they're doing it on their own. This is a circle of friends. This is a peer support network that has really been powerful for this boy.

So ongoing support. Middle school continued last year. We have four groups, instead of three. We had one group start at the beginning of the school year last year with a student who moved into the district. And when she transferred into our school, she had a lot of social issues, a lot of them. And in December, she reported that she had never been teased or bullied since she came to our middle school. And she said that she was teased or bullied every single day at her previous school, every day.

This girl feels safe. And we're finding that her levels of learning have expanded like you can't believe. She is now proficient and advanced on her testing; whereas, before people thought that she was cognitively disabled. So, I mean, we have made a lot of gains with her, and it is really exciting.

We also did this Chains of Hope fundraiser. And this was designed to get students with autism out in extracurricular activities. And so we just kind of created this idea of having the kids with autism join their peer support and come to basketball games and sell links.

And people could buy links like 3 for $5 or whatever. And then the proceeds of this will go partially to our group, partially to Haiti, which is a little bit of a youth service learning thing, and then one to the ticket holder in the group, kind of like a 50/50, but we made it a third, a third, a third.

And it was great because the kids with autism were out participating in activities in our school. They were coming to games. They had never been to a basketball game before, many of them. Now they are out interacting. They're selling tickets together. And it was just really cool.

And then we had a lock-in in March. And we had 36 students that actually attended. We played games and had a Wii bowling tournament at midnight. And it was crazy but a lot of fun. So I'm just going to show you a quick little slide show of what our activities looked like there.

(Whereupon, a slide show was played.)

Ms. LaBerge: So you can see we had a really great time. And what I find that is so interesting about these groups is that we have some kids serving as peer supports who aren't the most I guess socially accepted within different peer groups themselves, and then we have some of the most popular kids and the most athletic and the kids that everyone looks up to. And it's just so neat to have them all interacting with one another.

So currently we have over 60 non-disabled students participating in peer support programs district-wide -- this is 2 years after its inception -- 8 target students with autism and one target student without autism, who is in need of social supports.

And we have a new focus. This year we are going to be working on video modeling more, youth service learning projects, extracurricular activities, and then increasing those classroom supports to make their experiences in the classroom even more successful.

So our district-wide goals right now are to educate students without disabilities about social differences and encourage positive peer relationships in all settings. Education is the key.

And I think if everybody understands what the purpose is, that we want to increase social connections, during difficult periods of adolescence especially.

I heard so many stories from individuals with autism and their families about really bad situations, especially in the middle school with peers. And it's a way to bring people together, rather than have them operate in their little isolated groups.

And to encourage students to get involved in extracurricular activities with peer supports, having the peer supports helping to get them engaged, to reduce bullying and harassment.

As you heard from that one student, she hasn't been bullied since she has come to our school. That is amazing. It truly is amazing considering her social needs. And that is what we're seeing. We are seeing a climate change in this program that has been really neat.

And I have to say the efforts of all of our staff have been outstanding. And everybody is in it together. And it has been really neat.

So I have a quick little one-minute here video that just kind of summarizes what these kids felt.

(Whereupon, a video was played.)

Ms. LaBerge: So it's not only making a difference for the kids with autism, but it is really impacting many other kids who don't have autism in so many positive ways.

So thank you.

(Applause.)

Mr. Grossman: Well, thank you, Lisa, Jim, and Julie. That was great.

Questions from the Committee? All right.

Mr. Ne'eman: Yes. I have two quick questions for Jim. Just very briefly, I'm wondering if you can just reiterate what you think would be the most important requirements to put in place for peer support programs.

There is a lot of discussion. SAMHSA funds some things. Independent living centers exist. If this were to be done in the context of the autism world, what would be the most important requirements in your mind?

Mr. Sinclair: I would say that, first of all, you know, basic safety. You need to screen people. You need to train people. You can't just grab any autistic person off the street or out of a special education classroom and say, "Because you are autistic, you are an expert."

It needs to be autistic-run. You

know, it's not something that neurotypicals can do for us and call it peer support. They're not peers.

So I think quality control and being autistic-run are the most important factors.

Mr. Ne'eman: And then just the other very quick question was I wanted to ask if you had any comments on your co-presenters' presentations given I think yours was of a very different nature. I would be curious if you had any thoughts as to the other two presentations you would like to share.

Mr. Sinclair: Well, I think it underscores that people want to help, that they are trying to help, and that there are things that -- you know, the things that I am talking about aren't up there yet. There is no infrastructure for it. And that needs to change. So people are doing the best they can with what is there now.

Mr. Grossman: Any other questions from the Committee?

Dr. Huang: Thanks again for really terrific presentations.

I have two thoughts. One, your presentations are all so very different. And also in terms of thinking what does peer mean, that peer means very different things. Peers mean different things developmentally and so I guess having us really understand even better what that means: peer mentoring.

And then, to Jim's presentation, I am curious in terms of the autistic peer support. You named some things about what would be qualifications for that. There are in mental health consumer peer support specialists, who actually get paid and get reimbursed for their services. Is the autistic peer network approaching that or looking at a similar kind of certification process?

Mr. Sinclair: Not that I know of. I'm here telling we're kind of building things from the bottom up. We didn't start out in 1990 and say, "Hey, 18 years from now, let's be applying for funding and training and services."

Things have sort of evolved. And I think that other communities who have been doing self-advocacy for longer than autistic people have developed things that the autistic community needs to take responsibility on our own for picking up those aspects of those models that work.

I am not aware of that being done anywhere. As I said, I don't have a job. Possibly if I had a job, I would be working in something like that.

Dr. Crabtree: I just wanted to address a little bit the peers, you know, who are our peers. And I think whether it's an autism network or whether it's neurotypicals, I think that I look at peer relationships as people in the same age group perhaps being peers but not necessarily differentiating the people on the autism spectrum from the neurotypicals. I think that both have strengths that they can offer each other. And

I would rather look at it as partnerships perhaps.

So I think that you are right. And the way that we are defining peers perhaps might be a little bit different. But I think in order to develop programs that are really effective, I think we need to use the strengths from all individuals involved and create partnerships where we can provide those support services.

I am not sure I mentioned this, but in all of our programs, we incorporate feedback from the adults on the autism spectrum and from older adults, not college-aged students, but we do have some adults on the autism spectrum who are teaching our courses, who are providing opportunities to run the groups.

And we're trying to develop some more programs and apply for some more grants to develop a peer training network of the students on the autism spectrum who are attending Towson University to then become a core group to educate the faculty and staff on campus.

So I still feel like, though, that we do need to work in partnership. And that is how I would define peers.

Mr. Sinclair: What about training those autistic students? What about grants for training those autistic students to mentor other autistic students?

Dr. Crabtree: Yes.

Mr. Sinclair: You talk about training the faculty and staff. What about other students?

Dr. Crabtree: Actually, we're already doing that. We're using our students on the autism spectrum to train other autistic students. Yes. We are starting that but in partnerships, yes.

Ms. LaBerge: Just to expand on that a little bit, another evidence-based practice through the work that we have done with the National Professional Development Center is we are doing social skills instruction. And that is specific for kids on the autism spectrum, where we might have groups of three to four kids working with a speech pathologic primarily on developing those social skills that are needed. And then we practice them within our groups.

So we are giving them the skills that they may be lacking, but then we are giving them the opportunities to practice as well.

Mr. Grossman: Ari?

Mr. Ne'eman: Just one more question for Lisa. So you shared a significant amount of data as to the benefit of your programs for the mentors, the student mentors.

I wonder, do you have any data around the benefit of your programs for the autistic adult participants, particularly in the context of post-secondary education?

Towson is a very noted university. Do you have any information on improved graduation rates or improved academic opportunities or improved independent living skills for autistic students on the Towson University campus?

Dr. Crabtree: Not yet, but we are working on that. We have only been in existence two years. So the students on the autism spectrum that are participating in our programs have not graduated yet.

But that is the intention, to follow them over time and see if the experiences that they had in our programs will show any improved outcomes for them. But that is what we are hoping for.

Ms. Blackwell: Lisa and Julie, I am just curious, do you know of other programs similar to yours in the United States or are you guys kind of just unique? It sounds like you have sort of just mushroomed and started at the bottom and created some things.

Ms. LaBerge: You know, I have heard of different groups, like Circle of Friends and those types of things, that have developed. And I am not aware of how they are structured and if they are real universal.

What we have done is we have taken the evidence-based practice from the National Professional Development Center model. And we really tried to follow that. And we created, yes, this program from bottom up, but with that type of a process or a framework for us to do that.

Dr. Crabtree: There are college programs. I have been looking for other programs that are similar to ours. I haven't found any that are focusing on training the neurotypical college students to be a support system in the context.

Because there are more students on the autism spectrum now graduating from high school and attending college, there are programs at colleges, at some universities who are providing support services for that. Those are all varied. And it depends on where they are.

But there is no other program that I know of like ours. I would like to see it in every university.

Mr. Grossman: One more from Denise.

Ms. Resnik: Denise Resnik. I appreciated all of your presentations and particularly, Julie, the PALS program.

And to your question, Ellen, the Southwest Autism Research and Resource Center for nearly a decade has had a similar program. We're in dozens of schools throughout our valley and outside of the state. There are tremendous similarities.

And we also have collected data that not only demonstrates the social -- well, the social increases, skills increases in the individuals with autism but also the understanding of understanding of autism by the peers.

And, interestingly, we have had fewer reports from the principal's office because the neurotypical peers are also learning how to be nicer to each other.

So great program, and I hope to see

more of them.

Mr. Grossman: Well, thank you, Lisa, Jim, and Julie. I appreciate it. Let's give them another round of applause.

(Applause.)

Mr. Grossman: And we have one more presenter. Thank you all for your patience in hanging in there.

Ellen, are you going to introduce him?

Ms. Blackwell: Okay. I get to announce our final speaker, who we know as a very patient man. He is a Developmental Disabilities Director. So with us today is Director John Martin from the State of Ohio.

And, having spoken with John, I can attest to the fact that he is in many ways a visionary in terms of talking about what we started with this morning, which is trying to connect various systems.

So, with that, John, thank you for coming. And thank you for closing the day.

Mr. Martin: Okay. Thank you.

Thank you. It's a real honor to be here today. And I just have to say, by way of introduction, my father was a preacher for 45 years. And he had a compulsion about time, which I inherited, which is in the 45 years, he never once ran overtime.

So, as your closing speaker, I will try to zip through these because I know it has been a long day and you have heard a lot of really good stuff. And there's kind of a danger of closing the day with a bureaucrat.

So, just quickly, then, just a little bit about our state, one, we are a state that has lots of cabinet-level agencies. So when you talk about silos, ours run all the way up to the governor.

So, for example, I am appointed by the government. And I think I am the only State Director of Developmental Disabilities left in the U.S. that actually reports to a governor. So we have lots of state agencies.

Secondly, we are a home rule state, which is kind of interesting, which is that our local county boards are taxing authorities as well as service and administrative authorities. And over half of the local money that is totally raised in the United States is raised in Ohio.

And, to give you an idea of the extent of that, in the developmental disabilities system, the counties raise almost a billion dollars in local levy dollars that are voted on by their taxpayers while the state, my department, only puts in about 280 million. And there is some real significance to that. It lies here.

And that is that, like every state, we have taken many budget cuts. And, to give you an idea of the extent of the cuts, we have cut county board subsidies to such a point where if we get a 3 percent increase every year, it will take us 21 years to get back to where we were in '07.

So that will give you an idea of the extent of the cuts that have been taken, but what has protected us is that billion dollars of county board money has been relatively safe because it comes from property taxes. And property taxes are a much more stable predictable level of income.

Anyway, I am going to skip the demographics because others have covered those very nicely. And I don't think our demographics are significantly different from other states.

But the implications of our structure of many cabinet-level agencies are there are many touches by state agencies. And so if we look at individuals with autism between the ages of zero and two, you will see we have four different state agencies that might touch those individuals in terms of services.

When we go to preschoolers, you will see five department-level agencies could touch them with services.

School-age, we go to six department-level agencies that could touch someone with services.

And adults, we are back to about four department-level agencies that could touch someone.

And so when you have this many agencies that could touch someone in terms of services, that you have a lot of fumbles as persons pass from agency to agency. You have different philosophical approaches within agencies, service fragmentation, a real lack of accountability and finger-pointing, and certainly a lot of confusion, frustration, and anger on the part of consumers and families.

And, because of this, in 2007, then, our governor appointed what is called the Interagency Work Group on Autism to try to create a more cohesive system based on all of the complaints that we were experiencing from families. And our agency was asked to chair that group. And so here is what it looks like. These are the various cabinet-level agencies that participate.

In addition, what has been neat, we have had the Office of Budget and Management participates in it as well because there are lots of fiscal implications as we look across as well as the governor's offices attended our meetings as well.

A lot of our work was based on stakeholder input, both work that was done prior to '07 and then we have a stakeholder group that continues to inform our work as well.

The purpose of the group, then, is to develop more consistent approaches, smoother transitions to look at some guiding principles that we all operate under, irrespective of where we find ourselves in the system. Plus, we have incredible pockets of expertise in certain places of the state. And this enables those of us that don't have as much expertise to leverage it where it exists and then the fact that the reciprocal communications between the state agencies.

So we first developed a vision. And the one part, I just want to indicate what's underlined here, that our practices must be grounded in principles that promote across the life span an individual's opportunity for social connectedness and inclusion in every day as a valued and contributing citizen of the community.

And, as I will talk in a minute, we are feeling a lot of pressure for segregated service delivery systems. And so this becomes an important I think underpinning as we are looking at the services our various departments deliver.

Then we move from vision to mission. Again, it's talking about infrastructure to equip our many systems across the life span.

And then we have some guiding principles that we operate by. You see collective decision-making; problem-solving; a continuum of solutions; training, which has been talked a lot about today; good stewardship, which I will comment on in a second; and, again, open communication in a life span perspective.

So, just a couple of tangible goals that I wanted to talk just a little bit about and then give you a chance to answer any questions. We have four goals that we are working on. The first is to develop a policy framework to guide state agencies in development, improvement, and integration of programs serving individuals with autism spectrum disorders.

So what we are in the process right now is we are moving through each of our state agencies. And we are doing an audit of ourselves to see how we are measuring up to the principles and the other things that we laid out there.

And I apologize it has my picture on it there, but one of the things that we have put together is that because of the complexities, we have a single website, the Interagency Work Group on Autism, very creatively named.

But families can go to this. And like you can click on the right. And if your child is in age three to five, you can click on that. And that will bring up all of the different services that exist in the different governmental entities. So families can help find services as their child, son or daughter, navigates through the system.

In addition, we have promising practices on there, policy-making, keeping them informed of what we're doing. And I want you to note it has a survey placeholder that I want to comment about in a second.

Goal number two is to increase the availability of high-quality professional development opportunities for those who care for or serve persons with autism spectrum disorders.

Specifically, this is kind of an interesting one. And that is that when you have an entire life span of bureaucrats sitting together -- so you have RSC in the group, which does obviously vocational kinds of training.

And so the thing that RSC tells us

is that it is not skills that make it easy to get somebody a job in the competitive workforce but, rather, it is the ability to interact socially and social interaction skills that allow folks to gain much greater independence in the work area.

And so the question is if that's what they're telling us at that end, then how does that impact the type of services we deliver for early intervention? And should it? And they tell us, "Yeah, it should."

So, anyway, I'm probably taking too much time here, but one of the things we're in the process of implementing for a number of reasons is the play-based approach for early intervention services.

Now we're doing it for -- one reason is money. It's one of the cheapest early intervention services there are. And it's "We don't got no money." So that is one reason.

But what is more important about that service is that it supports the child in the first community that they are a member of, which is their family. And it teaches the family the skills to work with their child and to interact. And it really focuses on social, emotional development of the child through the play process.

But what we like about it is it starts turning the family into the expert and the advocate. So then as that child moves through the system, they are better able to help direct and guide those services. And if they're involved in it then, when we then look at our waivers in adulthood, which are self-directed and self-determined and family-directed, we have started with families early on in taking them through the entire system doing that.

And then that also connects very closely with our positive culture initiative, which we use in our adult all of our residential service model, which is an approach, again, of not using restraint, seclusion, timeout that has been talked about a lot today, but it is about developing styles of interactions and relationship. Again, it's a relationship-based approach, just as early intervention approach is a relationship-based approach, that really focuses on relationships and communication.

The other one, the next goal is to improve an individual's experience during critical life span transition points to move successfully across systems and settings.

An example of a tool here that we are using is something called a CAPS, which was developed by our own Shawn Henry in Ohio and Brenda Smith Myles. That is something that is being used in the school systems in Ohio. And the neat thing about it is, without going into detail, it doesn't matter what your philosophy is or what your approach is.

What the CAPS program is, it's a method of capturing the entire day. And it talks about the kind of supports an individual needs, the kinds of activities that they're involved in. And it allows anyone to see at any point in the day kind of the services an individual may be getting, the methodologies that are being used, the kind of reinforcers, issues related to sensory issues, et cetera.

The neat thing about this is that it provides a history of service delivery. And so it is kind of in some ways, you know, the new movement toward medical records and having a consistent form of medical records.

Well, we are starting to use the CAPS program in our early intervention process. And it allows again a way to capture what is being used and what is working for that individual so that then when that child goes to preschool, the parent can take that and show, "Here is what worked. Here is what didn't work. Here is what we would like you to continue doing."

And then when the child moves from preschool to regular school setting, whatever we call that, again there is a history of what has been used and worked. And the same instrument would be being used in the school system. So it starts to have this continuum of a way of organizing, capturing what has worked and what hasn't worked that we want to see if we cannot systematically then use it through our entire system.

And then just goal number four is to continue to collect information, to help us continue to improve our quality of services. And, as I mentioned, there are three different ways we are doing that. One is the national core indicators, which allows us to track kind of all of our services in satisfaction with those. There have been numerous examples of that given today.

I mentioned our Interagency Work Group on Autism, the inventory that we're doing to see how each of us are measuring up to the values and the purpose that we have all agreed to.

And then the last one -- and I noted back when I started on the website that shows all of those of doing a survey, one of the interesting things about being a home rule state is we have lots of different approaches being used in different counties.

And so what we want to do is to survey families in terms of what kind of approaches have been used with your son or daughter and get a sense of what their satisfaction has been with those approaches so that, number one, we can be better informed about what is going on as well as start getting a sense of some of the things that families feel are working.

So kind of then, in conclusion, what we have learned is that sitting together across agencies, across the life span are things that are incredibly important. And it helps all of us think about the consistency of services throughout our entire system as well as, you know, thinking from early intervention what we need to be doing so somebody can end up being competitive employed as an adult and that kind of approach is going to support that sort of thing.

And the importance of training

comes up continuously. And so it is another thing that we are working at, is putting together training programs with, again, consistent approaches across.

And so, lastly, how can CMS help? The first thing I would suggest is incentivize training. Right now our providers in our waiver programs and lots of areas, the way you get paid for training is it is built into the hourly rate as an administrative cost.

We think it should be something that could be billed directly as a service so that training is protected in the waiver program and doesn't end up kind of being as funding gets short, that it isn't able to be there.

Training is so important when you are dealing with complex individuals, whether it is autism or cerebral palsy or whatever but that importance of training.

So we would like CMS to partner with states to really incentivize training that would allow us also more ability to mandate.

The second thing is incentivize flexibility. And I think we are really seeing this and appreciate it and just suggesting more of that. We have taken as a state the approach of not doing an autism-specific waiver and also not doing a children-specific waiver but, rather, having a waiver that more goes through the life span. And to do this creates a need for some greater flexibility and some greater specialization of certain services in there.

Just the incentivizing of inclusion, you know, oftentimes for young children, you can take your Medicaid card. And you can go to a clinic. And you can get therapy in a clinic versus the kind of services that are provided in a home, family, education, family teaching, et cetera, which are much more difficult. Those services are much more difficult to do.

And then the last thing is that it is all about relationships and that the more complex the individual, the more important the relationship. And so how we incentivize those long-term relationships between those direct care staff and the individual that they are providing services to is absolutely critical, particularly as we move to serve more and more complex individuals within our service delivery system.

So I apologize for trying to rush through, but hopefully I covered most of the thoughts that were there.

(Applause.)

Mr. Grossman: Well, you are going to get quizzed by the Subcommittee now. So any questions for John?

Ms. Blackwell: I have a question for John. This is Ellen Blackwell. I don't think it's the same question, actually, but in ten years on, can you paint us a picture of what you think the system will look like and what you think the system should look like? I hope maybe it is the same thing.

Mr. Martin: Yes. It would be my

hope that we would see a lot more integration of our different service delivery models. So, for example, transition school-to-work, which we have talked a lot about here, the Rehab Services Commission, at least in Ohio, is really working on a lot of neat transition kinds of things. But the problem is that we have services commissions. For the most part, they are intensive, but they are only nine months in length.

And so what we are looking at -- and this is just one example -- is how do we model our waivers so that when RSC finishes theirs and some of our folks continue to need long-term supports, then how does the waiver program come in and mesh and support that work that RSC has started?

I think we are going to start at a much earlier age in terms of looking at what is needed to have folks successfully integrated into the community.

One of my concerns is that we are seeing some movement, at least in Ohio, for folks really, you know, demanding, which works well for a lot of kids but starting with the one-on-one ABA services for 30 to 40 hours a week. And then they become school-aged.

And in Ohio, you can get an autism scholarship. And so we're seeing folks move from that environment, then, to segregated schools, where the only folks who are in those schools are folks with autism. And so we don't benefit from some of the peer sorts of activities that were described earlier.

And now what we are seeing is that as folks start coming out of that, we're getting more of a demand for segregated residential settings when those folks become adult.

And so what I hope we don't see, Ellen, is a move to a more segregated service delivery system but, rather, that we are recognizing the incredible skills that folks with autism have, the benefits they bring to our communities, and that we need them as valued members of our communities participating with us in everyday life, as opposed to being segregated.

And so, I mean, that is my hope and my dream, that in ten years, we will see a totally integrated system with folks with autism and other disabilities being valued members of our community.

Dr. Huang: I really liked your presentation, and I really particularly liked these slides when you looked at the different agencies that touched people throughout their developmental stages.

I'm curious, though. I didn't see here something like the Office of Consumer Affairs or the consumer or self-directed, self-determination office. We have talked so much about that today and that being a core piece of a paradigm of services and supports. Does that fit into here or --

Mr. Martin: That's a good question. Number one, each of our agencies has our own consumer sort of system within it in terms of ways consumers give input, our policy, et cetera.

So we each have as individual agencies. And then on the slide back, we have then -- this, the Interagency Work Group on Autism, also has its own advisory consumer group that is made up of families, individuals with autism, and some professionals in the field that advise it as well.

Mr. Grossman: Ari?

Mr. Ne'eman: I'm really thrilled by much of what you shared with us. And, in particular, I am glad that you continuously mentioned the importance of inclusion, particularly because I think very often in the autism world, there hasn't been the same level of recognition of the importance of it that we have seen in the broader developmental disability context.

I was wondering, could you expand a little bit as to how at the state and federal level we can better incentivize inclusion, both for very young children in the context of early intervention and across school age and then also beyond into the adult service provision system?

Mr. Martin: Well, first, I think one thing that would be helpful would be a stronger voice at the national level about the dangers of segregation. I'm not maybe saying this right. I apologize.

It is interesting that Ohio has, as I mentioned, an autism scholarship program, which provides for segregated autistic schools. Now, not all of them are. And there are some neat things there. So I am not speaking against it, but there is no requirement against that kind of segregation.

To me, what was interesting, when this has been worked through the legislature and then additional folks wanting to have special Ed. scholarships as well, that the local advocacy community did not speak up at all in terms of raising the issues of segregation because they were too frightened by the autism community at large and the push of a lot of families to move in a direction.

So I am probably not stating it correctly, but I think a strong voice at the national level on this topic would really be helpful or at least ask the question.

It seems to me that there are a number of approaches being utilized that we're not talking about. We're not asking the question. We're not discussing it.

Mr. Ne'eman: So you're saying that there is a need to challenge proponents of segregation within the autism community?

Mr. Martin: Yes.

Mr. Ne'eman: Thank you.

Mr. Martin: That is just my opinion. I just want to say that.

Mr. Ne'eman: I appreciate you sharing it.

Mr. Grossman: Any other questions? Comments?

(No response.)

Mr. Grossman: Thank you, John. Appreciate it.

(Applause.)

Mr. Grossman: Well, I want to thank all of you. This was a rather daunting topic and a rather challenging and aggressive agenda that we put forward today. And the Committee understood that and realized that. And I appreciate everybody's patience as we struggled through this.

I certainly want to thank all of our presenters, the attendees, those that were listening over the webcast and on the phone, the OARC staff for your great efforts in putting this on today, and the IACC members for being here as well.

This I believe was a truly remarkable day. Ellen and I are very pleased with what we heard and what we saw. What we experienced was tremendous diversity in the representations and a flow that began to chip away at this very, very large behemoth of services and supports across a life span and how we have to work towards improving that to make it more suitable and delivering a system of care that is seamless and comprehensive across a life span for all those affected by autism.

This day has given us a lot to consider and certainly a lot to think about as we move towards making our recommendations to the Secretary. The Services Subcommittee will be meeting on November 29th -- mark that on your calendars -- to try and pull all of this together to put some sense behind this so that we can come up with recommendations for the December IACC meeting and hopefully then have something that we can introduce to the Secretary shortly after the beginning of the year.

I want to thank all of you for your patience, your attendance, your attention, and for all that you do to improve the lives of all those that are affected by autism. Thank you.

(Applause.)

Dr. Daniels: Thanks, Lee.

This is Susan Daniels, for those who are on the phone, from the Office of

Autism Research Coordination. I also want to thank all of our speakers for fantastic presentations today that will probably be very, very helpful to our Committee as they consider recommendations to the Secretary on services and supports. So I would just like to thank you on behalf of OARC and on behalf of the Committee for all of your comments.

The slides and videocasts from this meeting will be available on the IACC website within the next week or so. We still have to do some processing with the slides to get them up, but the videocast should be up within the next couple of days.

And, as Lee mentioned, the next IACC Services Subcommittee will be taking place on November 29th from 2:00 to 4:00 p.m. Eastern time. And it will be via phone conference call only.

I also want to remind you that parking validation stubs are available at the registration desk.

So, again, thank you so much for

joining us today.

(Applause.)

(Whereupon, at 5:37 p.m., the Subcommittee adjourned)