Wednesday, December 11, 2013

9:00 a.m. - 3:00 p.m.

**2013 ANNUAL COMPENDIUM**

**ON DISABILITY STATISTICS**

Held at:

Hart Senate Office Building

Room SH-902

Capitol Complex

Washington, DC

>> John O'Neill: Good morning, everyone.   
>> Good morning.   
>> John O'Neill: We're going to get started. Sorry for the delay, but there are a lot of people that aren't here yet. We thought we would wait a little bit of time to give folks that were having a difficulty getting here to arrive.   
 Anyway, I'm John O'Neill, from the Kessler Foundation, and I'd like to welcome you all here on behalf of the foundation, as well as the Institute on Disability at the University of New Hampshire. I think we have two thoughtful and informative workshops today. Both are funded by grants from the National Institute for Disability and Rehabilitation Research.   
 This morning's workshop, which is the annual compendium rollout of disability statistics, is a project of the Disability Statistics and Demographics RRTC at the Kessler Foundation.   
 The afternoon's workshop, which is the third annual Research‑to‑Policy Roundtable, is a project of the Employment Policy and Measurement RRTC at the university ‑‑ at University of New Hampshire's Institute on Disability.   
 A couple of notes before we proceed. Today, Deb Brucker will be presenting for Andrew Houtenville, and in the morning's workshop, as well as Jennifer Sheehy will be presenting for Richard Horne. Otherwise, the agenda remains the same.   
 OK. Kind of just to review the agenda for the day, this morning we're going to have an overview of the compendium. We're going to start with that. We have ‑‑ Deb Brucker will be sitting in for Andrew Houtenville on that. And we will be receiving some comments from Mark Perriello from AAPD, and then we'll proceed into the data workshop, which will last about an hour, maybe an hour and a half with questions.   
 Then we're going to have a lunch. And then in the afternoon ‑‑ the lunch will last from about 11:30‑1:00. Then in the afternoon we'll proceed with the Research‑to‑Policy Roundtable.   
 So thank you for coming. I'm sure there will be some additional people joining us as the day proceeds, and on that note I'd like to present Deb Brucker who will take the presentation from here. Thanks.

>> Debra Brucker: Good morning.   
>> Good morning.

>> Debra Brucker: Is this working? Yes? OK. I'm Deb Brucker. I work at the University of New Hampshire with Andrew Houtenville, and I am presenting his slides on the disability compendium. He cannot be with us today, and this is like his most favorite day of the year, if you know Andrew; he loves the compendium. So I feel badly that he can't be here, but I will try to share the compendium information with you.   
 Just so you're aware, when you checked in you probably saw we have stacks and stacks of this compendium in a hard copy. We'd like you all to take as many as you can home with you so that we don't have to take them back to New Hampshire with us. Great Christmas presents.   
[Laughter]  
Wrap up.   
 Also, there are USB drives up at the registration that have not only this compendium, but past years' compendiums loaded onto them, as well as all of the presentations from today. You're welcome to take those as well.   
 So welcome, officially, to the fifth annual release of the compendium. As John mentioned, it's presented by the RRTC on Disability Statistics and Demographics that is led at the Kessler Foundation and funded by the National Institute on Disability and Rehabilitation Research.   
 The purpose of this presentation is to describe what the compendium is, discuss anything that's new this year, highlight some of the patterns and trends that we see when you go through the data in the compendium, solicit some input on additional topics that we might include in next year's compendium, talk about some ways you might use the compendium, and then mention how you can access the compendium and technical assistance that we provide at the University of New Hampshire.   
 So the purpose of the compendium is to provide the disability community, so advocates, researchers, service providers, with a comprehensive set of statistics in one place that they can access around different topics related to disability.   
 It's a guide to existing sources of data and statistics. We just pull the data from other sources that exist. We use both population or survey‑based data as well as administrative data. And it's modeled after the statistical abstracts of the US, which I know Andrew always mentions is like something he loved to read as a kid.   
[Laughter]  
His love of data. I have to mention that specifically.   
 So the compendium is designed to have a comprehensive set of tables with, first, a descriptive summary page in the hard copy document, then the tables will follow those descriptive pages. It's based on existing published statistics with references to the original sources. So if you need more information, we'll give you the links that you can click to get that original source information.   
 You can also access technical assistance via a toll‑free number. So if you need help interpreting the statistics or if you need the statistics in a different way or format, you can contact us through that phone number or also on our website, and we will get back to you.   
 We do have a particular focus on state‑level statistics and national trends. A lot of the technical assistance requests we do get are from people at the state level asking for state‑specific information.   
 So the current compendium includes the topics that are listed on this slide, population size and prevalence of persons with disabilities, employment, poverty and wages/salary, veterans statistics, health insurance coverage, health behaviors, other health statistics. We use administrative data to provide information on the supplemental security income, Social Security disability insurance, Medicare and Medicaid. We also have information on special education, both vocational rehabilitation and federal government spending.   
 We are looking to expand the compendium for next year, so if you could think about some additional topics that we might cover next year and either find me at lunch or you can e‑mail us afterwards, that would be helpful. We can get your input.   
 There are a couple of cautions we like to mention when people grab the compendium and zero in on one statistic, is that you need to pay attention that the data come from different sources that have different methods of identifying people with disabilities. Some may use a work limitation question. Some may use a series of six different questions that look at different limitations, for example. So we do include a glossary in the compendium that has a definition of all of the terms that are used in the tables. Similarly, with employment and unemployment, those can be defined in slightly different ways. Again, you should check the glossary if you're trying to interpret, or contact us for technical assistance.   
 Next I just wanted to provide some basic statistics from this year's compendium, just to set the stage for the rest of the morning. So this slide shows the number of people with disabilities in the US is 38.4 million, or 12.3% of the population. This is based on identifying people with a disability as someone that has either a seeing, hearing, cognitive, ambulatory, self‑care or living limitation.   
 This slide shows since 2008 the percent of people that have a disability has increased from 36.1 in 2008 to 38.4 in 2012. But the actual percent of the population has stayed fairly steady, from 12.1 to 12.2. Even though the actual raw number has increased, the percentage is similar.   
 This slide shows the numbers of people by disability type, using those six questions that I mentioned earlier, in 2012, age 18‑64 living in the community. People can identify more than one of these types of limitations. So that's important to note, that people can respond that they have both a vision and ambulatory type of limitation. You can see the ambulatory is the highest level. Something our office spends a lot of time working on is employment statistics for people with disabilities. So this next slide shows the employment rate by the disability types that were listed on the earlier slide.   
 The employment rate is people that worked over those that are in the labor force. You can see that it's highest for people with a hearing limitation, at 49%, but lowest for people that have a self‑care independent living limitation, at 16, 15%. All of that is compared to people with no disability that have an employment rate of around 74%.   
 This next slide shows employment rates since 2008. So kind of spans over the time of the recession. So you can see in 2008 with the level of employment was, people without disabilities was about 78%, and people with disabilities was about 39%. Employment dropped for both of those groups in 2009, 2010, stayed pretty steady in 2011, and is creeping up a little bit in 2012, a little bit more so for people without disabilities. People with disabilities are still staying at a fairly low level of employment, around 33%, which is really where their employment rates are bottomed out in 2010.   
 So again, this is data that you can pull from the compendium. It's not displayed in this actual format in the compendium, but the tables and information is all in the compendium.   
 We also include some trends in labor force participation in the compendium. This is for people age 16‑64 living in the community. You can see that the gap in participation in the labor force has remained fairly steady from 2008‑2013. The labor force participation is different than the employment rate. Labor force participation includes people that not only are employed but also looking or wanting to work as a proportion of people that are working age.   
 This next slide just shows the level of the gap in the labor force participation between persons without and persons with disabilities since 2008. The gap has been around 42%, 45% from 2008‑2013.   
 We also, as I mentioned before, include administrative data in the compendium. So for example, information on applications to SSDI. You can see how the raw number of applications has continued to increase over the last decade.   
 In addition, we have some information on federal expenditures tabulating the cost of disability to the federal government. We have 2008 information in the compendium right now, and in the next couple years we'll be updating that study, providing more recent data on the federal expenditures for persons with disabilities.   
 We did start something new this year in cooperation with John O'Neill's group at Kessler and UNH. We've started a national trends in disability employment report. We call it the TIDE report. It's a press release that comes out the first Friday of every month to coincide with the labor statistics that are released, and it focuses on employment for persons with disabilities.   
 We also, thanks to funding from NIDRR, we will be releasing the compendium for the next five years. We also will be enhancing it including an annual report on disability, sort of a higher level progress report, expanding topics, as I mentioned before, and adding some more detail and indicators.   
 So to access the compendium, in addition to the hard copy we provided and the USB drives, we also have a website, www.disabilitycompendium.org. There's accessible PDF and accessible HTML where you can download some of the tables. We do have more print versions back at our office in addition to the ones out at the table, and Penny Gould, our administrative person, asked if anyone wants a boxload mailed to them, we're glad to do that. Come see her or me during the break.   
 Then there's also the technical assistance phone number is 866‑538‑9521 that you can contact us for assistance in accessing any of the statistics.   
 So this is Andrew's contact information. If you want to send him a quick hello, you can use this information. My e‑mail is debra.brucker@unh.edu, if you have any follow‑up questions.   
 Now I'd like to turn it over to Mark Perriello, President and CEO of American Association of People with Disabilities for his comments.

>> Mark Perriello: Hello, everyone. I'm going to stand behind the podium, if that's OK. Thank you, Deb.   
 First and foremost, thank you for joining us today. You know, it is a pretty exciting day in my book too, because I think doing statistics you need good data, you need good research in order for groups like AAPD to do all of the work that we do. It is so helpful and so needed to be able to walk into a room and have really intelligent conversations and have great data like this to back it all up.   
 First and foremost, though, I want to thank Andrew, who can't be with us today. Thank you, Deb, Penny, everyone from UNH for all of the work that you all have done to put this great research together.   
 I also want to thank the Kessler Foundation, John and your team for the work that you all are doing and the work that you are going to enable UNH and others to do for the next few years. Very, very important.   
 Also want to thank Senator Hatch, John Connelly, and the team from AAPD, Henry, who I don't believe is with us yet, but Henry Claypool, but also over there two folks that had a lot to do with making this day come together, Colin Schwartz and Brianna Gross. Thank you both.   
 The thing I wanted to talk a little bit about today, why are we here, what is it we're all doing here together and what is it that we hope to get. The thing that we need, right, is new and more powerful outcomes for people with disabilities. One of the things we were talking about just before we sat down today was that there's no surprises in here. Right? The stats don't really reflect a lot of new trends, a lot of new information. It's a little bit more of the same.   
 One of the things that I think is interesting, right, if you talk to employers, you really would get the impression that everything is rosy, everyone wants to hire people with disabilities. Everyone puts on a veneer that this is so important, they attend the ADA trainings, they check a bunch of boxes that show they're doing everything they're supposed to be doing in order to hire people with disabilities, but the outcomes aren't really there.   
 So even as the economy has started to pick up pace, we continue to lag behind. So we need to do some new things in order to produce some powerful outcomes for people with disabilities, so that one day when we're having the coffee conversation before we all sit down and look at the statistics, we get to talk about some great surprises, some great new trends in employment for people with disabilities or access to healthcare.   
 So that's what we're focused on at AAPD. I want to talk a little bit about some of the things we're doing to try to change those outcomes, then also look at some of the bright spots that are out there, right, things people are doing right, so that we can see more of that in the future. And ultimately, again, sit down here, right, at one point over the next five years and say, Look at that spike. Look how many more people are employed now than have been in the past.   
 A lot of that, as we all know, is dependent on the economy continuing to improve, but I think there are a lot of things that we can do to really yield positive outcomes. That's what we're about at AAPD, is really changing the paradigm for people with disabilities.   
 So some of the things that we're doing, and I think probably the one that is most relevant to a lot of folks in this room ‑‑ though before I make that assumption, it would be helpful just if you could give me a little bit of a show of sort of who you all are. Are there folks here in the research world?   
 All right. What about sort of the feds?   
 There can be overlap, right?   
[Laughter]  
 Folks on the Hill?   
 Folks from the community or advocacy world?   
 All right. So I'm going to try to talk to all of you, but that might be a bit of a challenge, because you come from all walks of life, but ultimately we're all here for the same purpose, I think. We want to really figure out how to drive some outcomes for people with disabilities.   
 First and foremost, Henry Claypool joined AAPD from HHS. He's our executive vice president. He is absolutely outstanding. He knows this, these subjects inside and out. One of of the things that, thanks to his leadership, we're really pushing is decoupling of benefits from employment through SSDI. That's the vehicle we've chosen to drive this.   
 Ultimately, so many people with disabilities face enormous decisions, really, about whether they're going to continue to get benefits or take a job, right, where their health coverage might not necessarily meet the needs that they have in terms of being able to live independently.   
 So what we're really sort of postulating is that there is a way to remove that question. Basically, by saying as people enter the workforce that what they can do is actually not have to give up that government benefit, but as they move through their career, as they start to make more money that more and more of the burden shifts to the individual. Right?   
 So rather than it being very black and white, you're either in that income category or not in that income category, it is more tiered. So that more people can enter the workforce. And I don't know if folks know, but this is such a real problem that there are schools, colleges and universities, dedicated to young people with disabilities, and I'm going to not use names here, but graduating seniors who actually train on how to apply for government benefits.   
 So they go through, right, get this tremendous education and, right, at the end, Oh, by the way, you need to know how to apply for some of these programs, because you're not going to work, because people aren't going to give you that opportunity.   
 So that is a very, very real challenge, and it's a real challenge for a lot of people, especially if they need those services and supports in order to live independent lives.   
 So this, right, would create something that allows them to start on the path to success, but then continue to shift more of that burden again to the individual and away from government. It could a very, very powerful game changer.   
 So Henry, I think, will talk a little more about that when he is here this afternoon. So I hope that you all can stay with us this afternoon when he is moderating the panel.   
 One of the things that we're doing, though, because I really believe that solutions don't just come from government, they come from the private sector, we are partnering with a group called the United States Business Leadership Network. I don't know how many of you are familiar with them, but they're an absolutely outstanding organization. They have affiliates throughout the country. They're really a business‑to‑business network of professionals working to try and hire, recruit, retain, build inclusive cultures in the workplace for people with disabilities.   
 What we're doing is we have launched and we're in the pilot phase of the disability quality index. From my point of view, this is one of the most exciting projects that AAPD is working on right now. So what is the DEI? The DEI is inspired by work at the Human Rights Campaign, corporate equality index, and what it is is going to be a rating system where we are actually out there providing a score to companies on how they're doing on disability practices, ranging from hiring and recruitment to retention, to leadership, to marketing, to accessibility, both infrastructure and online. Really, the whole gamut.   
 It takes, really, something very inclusive, something very broad, right, can't just be one piece here, one piece there, but what is the sort of total package that a company needs to be looking at in order to be doing right by people with disabilities.   
 As we often say, even though there is a rating, if a company is participating in this effort, from my perspective they're already doing the right thing. They're already stepping up to the plate, putting themselves out there, taking the risk, right, to learn how to do better for people with disabilities. It's really going to be a great educational tool.   
 As I mentioned, we have launched it. We're in the pilot phase right now. We had a goal of having 35 companies participate, and we're up to 50 companies right now that are in the pilot. Part of being in the pilot is they get to be anonymous, because they're helping us build a better tool, right.   
 We are giving them sort of free pass the first time out. But what is powerful is we're talking about leading companies in telecom, in entertainment, in retail. It really runs the gamut. So really great companies that are stepping up to the plate to help us refine this. It was actually built by people with disabilities and by people in the business community. Together we had a really powerful advisory board of folks from all various industries, community representatives to come up with the questionnaire.   
 One of the things that I will add is that going along the lines of that this is an educational tool, the first time people get a score that score isn't actually public. What will happen is we will work with companies for a period of 6‑8 months to help them improve that score. To me that's the opportunity. That is the chance for us to actually get folks to really think hard about what their practices around disability are, to get them to make changes, so that on the tail end when that score comes out it's a higher score, but ultimately they're doing things differently to change outcomes for people with disabilities.   
 The second thing I'm particularly proud of is the work that happened recently to get 503, revised rules on 503 implemented. So 503, I'll just be very brief on this, because I think probably all of you know, is going to require federal contractors to set a hiring target for people with disabilities of about 7%. This effort had been going on for so long. So many people, community folks weighed in during the notice of proposed rulemaking, businesses weighed in. We finally have this final rule.   
 For folks who don't know, federal contractors represent 22% of the American workforce. 22%. This 7% aspirational goal has the power to be a huge game changer if implemented well.   
 There's a big "if" there, right? Lawsuits are already being filed. Day one is sometime in March, so it isn't quite in effect yet. But there are people out there in the construction industry, right, asking the same old questions: How on earth can someone with a disability work in construction?   
 Well, that's a very myopic view of disability. We all know that. So what we need to do, actually when I say myopic, is really educate employers, educate folks to let them know that there is a way to change these numbers, that it's good for business and good for people with disabilities as well.   
 So 503 is going to be a big focus for AAPD moving forward, and I know it's going to be a big focus for a lot of organizations in the disability space as well.   
 One of the things that we work on every year, and it's changing, becoming even more effective and more powerful, is Disability Mentoring Day. It was actually founded by the White House back in the 1990s, transferred over to AAPD in 1999‑2000.   
 We this year brought together over 17,000 young people. I shouldn't say brought together, but engaged 17,000 young people from across the country in mentoring, job shadowing. On the third Wednesday of each October we do this program.   
 This year, we're changing it into a yearlong program. We have 111 coordinators from across the country. What we want to do is really take that one‑day experience and turn it into something that lasts all year, because that's how we're going to change outcomes. The younger we engage folks in the conversation about their careers, the more likely they are to go on to successful careers.   
 I will never forget, I was at a Senate hearing once, and I forget the topic, I apologize, but the young woman testifying, she had cerebral palsy. One of the things she shared was that when she was growing up, not once, not once did anyone ever ask her what she wants to do when she grew up.   
 That is something that we take for granted, so many of us, right? You have those conversations, you want to be a firefighter or nurse or doctor. As you get older, it becomes more complex, but that question, right, that dream is something that so many of us just is a natural part of life, that for people with disabilities isn't necessarily always there.   
 So that's why PMD can be such a powerful tool, because you are talking to young people about their future, and saying that they have a future, and that future can be anything that they want if they put their mind to it.   
 So really, really powerful program, right, but as folks come out through the educational system those numbers are going to change over time. We aren't going to see that immediate impact, but it will have an impact. I think as we focus on young folks transitioning from education into the workforce, that is where there is so much tremendous opportunity as well.   
 One of the things that we're doing is trying to provide more opportunities for people in very specific career paths as well. So we just this year launched the NBC Universal scholarship for people studying media and communications work. We gave out four scholarships, $5,000 each. It's named after Tony Coelho. It was his brainchild.   
 Really, the goal is that for us to make change, one of the things we need to change is societal attitudes. So this scholarship, right, is helping put people in place in professional settings where they will eventually go on to make a difference in that dialogue, whether they are working for a television network or a small communications firm or polling firm. Having people with disabilities will make a big difference, because for so ‑‑ just across the board, you can think about it, in polling there's just a dearth of people who ask if someone has a disability when they're conducting their polls. Right? So having people that think about that is important, right? When you're looking at television networks and the stories being crafted for the American audiences, that is so critical that there are people with disabilities who are making sure there are more characters with disabilities who are on the screen.   
 That work is already happening in a big way. I was actually ‑‑ just, as a quick aside, one of my favorite shows is "Grimm." I will confess. They had a deaf character on one of the recent episodes.   
 You know what ‑‑ people don't do that. They just don't think about that, right? But disability is such a natural part of life. If you look at the ‑‑ if you're watching television or a movie, it's not something that you see very often. I was so impressed that ‑‑ it was one of the not main characters, but a significant character in that episode. What a great thing to see, but all too rare.   
 So that's one of the things that we want to change, because I think ultimately it's going to help change these statistics, because people when they are more comfortable with people with disabilities will, I think, make different decisions around hiring.

So one of the things that I have in front of me, really quickly, is what are some of the concerns that people have when hiring? I think we need to address those concerns in a real way in order to make change.   
 This was from a recent poll that was done with HR managers. 81% said that they were worried about the cost of providing reasonable accommodations. Well, we all know that the cost of an accommodation is not that significant. The average cost of an accommodation is $35.   
 80.9% said they don't know how to handle the needs of a worker with a disability on the job. That goes to why we need to change societal attitudes.   
 80.2% said they are afraid they won't be able to discipline or fire a worker with a disability for poor performance. Well, that goes to the educational piece. That's why things like the DEI and other tools out there are going to be so important for the community moving forward, because we need to educate folks and we need to educate folks in a new way, because as we sort of talked about there is this veneer that everything is rosy, but the outcomes aren't there yet.   
 This keeps going, but the last one I will share is 73% say they can't ask about a job applicant's disability, making it harder to assess whether the person can perform the job.   
 So again, that goes to the education piece, right? For federal contractors specifically, now they're actually going to have to ask the question and legally can ask the question. That is a pretty exciting game changer, I think, for a whole host of reasons.   
 So the other thing, those are some of the problems, but what are some of the bright spots? What are some of the places that we can look to that are really game changers for the community that can be replicated?   
 One of the first things I will say is, looking at government, the President's executive order, they're meeting a lot of success hiring people with disabilities at the federal level. They need to do more, but that could be replicated in all 50 states. It could be replicated in counties. It could be replicated in cities and towns across the country. So taking something that is an effective tool and replicating that.   
 Section 503, which we already talked about, I think is a tremendous bright spot, but something that also could be replicated. There are contractors who work with cities and towns and work with state governments. How can we take this model and take it to different places throughout the country in order to see even more change in the future, so again those stats start to move?   
 The NGA, National Governors' Association, had a huge workforce initiative this year around people with disabilities, called "A Better Bottom Line," where really from my perspective the dialogue started to change. It was with the right people. It was with the decision makers. That again can be replicated at state levels, replicated at the town level, it can be replicated around the country.   
 What we need to do, what AAPD is working to do, is trying to do just that, which is really see these models, see these bright spots expand, rather than just having them be one‑offs.   
 Finally, I would say there are private sector companies doing right by us as well. If you look at the work around Walgreens, they started with a 7% hiring target in their distribution centers. Now they have a 10% hiring target for the entire company at all levels, and that is absolutely outstanding.   
 It was incremental, right? They started where they could. Randy Lewis, who was with Walgreens, sort of the brainchild of this effort, they started where they could. They started with the distribution centers. They got a lot of feedback for that. He was able to show the success there, then expand to the whole entire company. So taking a company like Walgreens, taking their model to other employers, I think, is something that you will see a lot more of in the future. Toys R Us recently followed suit. I think we will see other companies start to do the same as well.   
 But ultimately, what does this all mean? It means that we need more nuanced approaches to the work. We need to take a look at the bright spots and make them shine, make them shine wherever we can, because that is what it is going to take to make real change. We need more nuanced approaches, because black and white doesn't work. Black and white isn't getting us where we need to go, but a nuanced approach can.   
 So I think you will see really a changing tide around this work, because I think a lot of folks who have been working hard for a long time on these issues are starting to see results in a really profound way. AAPD is there, has been there as a part of that, and will continue to be. Ultimately, we will have great research to back up all that we're doing, and hopefully this research is really going to reflect a lot of positive change and a lot of positive change for disabilities in the future.   
 I thank you all for a really great workshop session. We're going to hash through these statistics. That will be a great dialogue as well. So enjoy yourselves. Hopefully we'll all learn quite a bit. Thanks.   
[Applause]

>> Debra Brucker: We'll move on to the workshop portion of the morning. Are you going first, Matthew? OK. This is Matthew Brault. I need to get the slides from here.

>> Matthew Brault: My name is Matthew Brault. I'm with the health and disabilities statistics branch of the US Census Bureau. We're responsible for putting out a lot of the data that you find in this compendium. So I'm going to talk a little about some of the data releases in the last year, and talk about some things that you can expect in the near future.   
 In this past year we've put out a major tabulation called Disability Employment Tabulation. This was a joint effort between the US Census Bureau and Department of Labor, specifically Office of Disability Policy, Office of Federal Contract and Compliance Programs. What it was, it was a series of cables that used the 2008‑2010 American Community Survey data. It's all on the Fact Finder.   
 The seven tables touched upon detailed applications, the EEO application, job categories, federal sector job groups, state and local government job groups, educational attainment and age crossing, then probably the biggest table out there in the package was looking at employment statuses and earnings for detailed occupations. Each one of these different tables were crossed by disability status, sex, race and ethnicity and citizenship.   
 So it's getting to a very fine detail at some small geographies as well. Looking at this as nations, states, CESAs, sometimes called core‑based or metropolitan areas, public use and various county sets.   
 A lot of very detailed information if you ever wanted to look for a specific occupation type and look at how many people with disabilities versus those without disabilities, men with disabilities, white men with disabilities, and you can really get into a lot of very fine data in this table package. Basically, it was modeled after the EEO tabulation. The Equal Employment Opportunity Commission does a tabulation of Department of Labor, Justice, they contract with the Census Bureau to do tabulations both with their own use in doing compliance work making sure that companies are in compliance with various EEO laws.   
 So we took ‑‑ that is based off the five‑year data set. I'll get into that later, but this is using three‑year data and touches on a lot of the same crossings, but we've added that disability component to the tables that weren't there before.

Some of the interesting things we get from this is you can see ‑‑ it's a little bright. Some of the most common occupations for people with disabilities, and you find that janitors and building cleaners are the number one occupation for people with disabilities, with a little over 300,000 workers. Also near the top are drivers and sales workers and truckdrivers, cashiers, retail salespersons. You do find there's a lot of sort of in the same kind of area, so a lot of things in service industries, things like that.   
 Then we can look at what the occupations with high prevalence of disabilities. It may not be those that have the largest number of workers with disabilities, but within those occupations have the highest percentage of people with disabilities. We find that cutting workers had the highest ‑‑ of workers that there are at least 20,000 in the United States, cutting workers had a disability rate of a little over 16%. We also find that crossing guards had high disability rates, motor vehicle operators, dishwashers, things like that.   
 You could also break these out by the EEO occupation groups. This is where we see that those service workers were the number one group. But we also see administrative support workers as a very large number of workers with disabilities.   
 When you look at the earnings distributions, you can see that there is a definite shift where people with disabilities earn less than those without disabilities. One of the interesting things in this is how much does occupation play a role in that earnings distribution. You can see that even among certain occupation types you see that shift, but sometimes it's there, sometimes not. Among janitors, you find that janitors with disabilities earn less than janitors without disabilities. But the distribution for cashiers looks almost identical, that there really is almost no earnings differential between people with and without disabilities.   
 So in addition to other things from the American Community Survey, in this past fall we put out our one‑year and three‑year estimates for the 2012 data. These are all in the Fact Finder, so another year worth of data we put out.   
 I really was hoping for this event to be able to show you stuff from the five‑year data. Because of the shutdown in October things got pushed back. Our release went from the week before this event to the week after this event. Just that two‑week difference, but kind of affected what I can include in this presentation.   
 If you check the Census Bureau's website next week, we will be releasing the first five‑year estimates of disability status. If you remember, the Census Bureau changed the questions on disability status in 2008, which caused the discontinuity in the disability series. As a result, the aggregate, we couldn't do the data from the multiple years to get smaller geographic areas.   
 This year with the 2012 data, this is our first five years of continuous collection on these questions. So we can now start putting out detailed information down to very small geographic areas.   
 So December 17 is when these data are being released. We will have information for all counties in the United States, all places, all census tracks. We have block group data. If you really wanted to get very, very, very small geographies, you can. The block group are not on American Fact Finder, but in summary format for researchers who want to get to that.   
 Just reiterating, because we know a lot of people are approaching this five‑year data file, from conversation with people at the Department of Justice who want to use this information, just reminding people these are different from what was in Census 2000. Census 2000 being the last time we actually had a census track level data for disability. So they're really not prepared where you can take one and say that disability is increasing, it really is a different measurement.   
 We're also focusing our report on working with the disability as a focus for using these data this year. We're looking at expanding stuff from the disability employment tabulation, looking at occupations and industries and levels of work, and using the very large sample that provides to very small groups and get a lot of very good detailed information about characteristics of workers with and without disabilities.

On that same topic of small area disability estimates, since we know that ACS definition of disability only captured very poor aspects of disability, it's not a very comprehensive measure of disability. The Census Bureau has been looking towards methods of combining information from the program participation with the American Community Survey in some kind of model‑based estimate to look at state and county level estimates of disabilities for more comprehensive measure.   
 The Survey of Income and Program Participation that is the survey that produces the number 56.7 million people in the United States with a disability. It's also the survey that produced the number that the ADA cited in 1990.   
 So we looked at a couple of methods. One was the bivariate area level model. I won't get into details about how this works. This is the method being used by the small area income and poverty estimates program, small area program with the Census Bureau. Basically, relies on taking some survey‑based estimators, combining with a whole array of auxiliary data, a lot of things from the programs to kind of help model them on variance on the estimate.   
 The other method we looked at is the regression projections method. It's almost like a method where you take things with high correlation, compute the information onto ‑‑ from the SIPP onto the ACS and use the ACS as a vehicle for tabulating the smaller area models.   
 We did a study of the regression projection methods for a paper presented at the joint statistical meetings this past summer, where we basically found that there were some problems with the method. We're looking into some ways to kind of get around those problems, just the fact that a lot of the variance reduction was model specific. So complicated way of just saying that we still have a lot of work to do trying to get something useful out of this.   
 We also have SIPP 2.0. They keep changing the name of what this is. It started with what they called the reengineered SIPP, then SIPP on the history calendar. I think it's just going to be called the SIPP again, even though it's a very, very different survey.   
 With this new SIPP the disability questions that were part of it kind of go away. In the past we were able to use a supplemental questionnaire. It was a topical module that focused on adult and child functional limitations. There are no topical modules in the new SIPP. It's all going to be one core survey. They tried to incorporate as much of the topical module content into the core survey, but they couldn't put the real wealth of information on disability status into that core instrument.   
 So the disability questions that are in this new survey include the core ACS questions, the six questions that you see in a lot of surveys. It includes some questions on developmental delays for kids under the age of 5, some questions about difficulty playing with other children and limitation in schoolwork for children, then looking at some of the employment difficulty questions that are also on the survey. This all goes into the field next year.   
 Now, I should say that the questions are ‑‑ there are no topical modules, but that doesn't mean they can't use the SIPP as a vehicle for other things. The Social Security Administration is currently paying Census Bureau to develop and field a supplement to the SIPP, and they're including a number of the topics from the topical modules that they use for a lot of their projection work and things that they need. That includes things like the pensions, stuff about marital histories, then the work disability history topical module and adult and child functional topical modules. These are coming back as a separate module, as a separate survey. It's a supplement.   
 It is going to be fielded slightly different. It will be a telephone‑only survey. Because of that, we will have a few modifications and improvements to the survey. One of the things we're particularly proud of is we're changing the way in which people can report the type of conditions or conditions that are underlying the disability. Before, it was a list of about 29 topics and people tend to just ignore the 29 topics, mark "Other," write things in, which presented a problem because the Census Bureau didn't have money to do a coding operation. We just had "Other" as the number one group.   
[Laughter]  
Yeah, which never looks good.   
 So with this one, we're doing almost like an auto coding operation, where similar to the way Census Bureau questions ask about place of birth. If you say what country were you born in, the person says Kazakhstan, the field rep will type in K, will will abbreviate to every country that begins with K. They can have a shorter list, click a button, that one country that will get filled in. It will be automatically coded right then and there in the instrument. We're doing that now in the list of over 400 conditions that are based from the ICE‑10, the codes that accompany them is ICE‑10 based. So if you were to write a ‑‑ let's say the underlying condition was cerebral palsy, start typing in c‑e‑r, shorten down to the list, you can see there, click the button, and this will get the ICE‑10 code for cerebral palsy.   
 This involves minimal work for the Census Bureau's coding operations, because it's already been coded, and effectively we want to reclassify conditions in different ways we could. So after we can then say we want to group things this way, we want to say these ICE‑10 codes get this classification, these get another classification. We can have one way to classify diseases or conditions. Then we can ‑‑ someone else can come in, they can say, Well, I need it broken down slightly different. You can then have multiple different types of classifications. We wouldn't have the problem where they were already grouped into one set of classifications and we wouldn't be able to break them out again. We're pretty proud of that particular improvement in the instrument, and it would be great to see that when we get the data back from that.   
 Here are links. I think these slides are all in the USB slide. If you get these presentations, which we can get all of the links from that, both the data in the American Fact Finder, go to the equipment tabulation, and basically our disability page on the Census Bureau where we have all of this information.   
 This is my contact information. You're welcome to give me a call anytime, send me an e‑mail, I'll help you find anything you're looking for. Happy to take any of your questions.   
[Applause]  
>> Brian Armour: Good morning, everyone. My name is Brian Armour. I'm with CCD, Centers for Disease Control. I've been here ‑‑ if you've been here the last several years, I'm a regular fixture at these things, along with Matt, Terry. Matthew and Terry.   
 I always feel like they all go by because I'm here talking about health, everyone else is talking about employment. But as someone once said to me, health is key to employment. So I think there is room for me, and I'm glad Andrew continues to invite me.   
 In years past I've talked about disability and health surveillance systems, which we launched a couple of years ago. What it does, it provides data for every state. It is called for in the Institute of Medicine reports. We finally delivered on it a couple of years ago. For each state you can see, you can look at people with and without disabilities, and you can see disparities that exist.   
 What we've done this year is we've added a feature called Upstate Profile to that. Now you can go in for a particular state and look at a number of indicators across within that particular state, which is a new feature. That's DHDS, Disabilities and Health Data System. Dhds.cdc.gov.   
 This year I was asked to think about something different; I was asked to think about a problem of program this year, demonstrating program value. Let me move to the next slide. I'm not sure how well you can see these slides, so I may be reading them to you.   
 Basically, it's a conundrum many of us face. We have state programs. In our case, 18 states. Within these 18 states, they're doing terrific work trying to improve health and wellness for people with disabilities. What we get are a bunch of results. We don't get health icons, and it's difficult to show impact. So I've been asked to think about that problem. That's what I've been working on this last year. I think I have a proposed solution to that problem. It could be a little provocative, I hope it's not, because the intent is to improve health and wellness for people with disabilities. Thank you.   
 The intent is the improved health and wellness for people with disabilities. Keep that in mind. Also, these are my thoughts and opinions. CCD has not endorsed them as of yet. I'll remind you of that at the end also.   
 What we have is we have these 18 states, as I said, and they're doing great work, but how do we demonstrate the value of the work that we're doing? How do we tell our story? That's real difficult. Because we went to each state, said, Whatever your needs are, we want you to work on improving health and wellness for people with disabilities within your state based on what their needs are. Now we're coming back, saying, You need to demonstrate the value and impact of these programs, and that's quite difficult when the needs can vary across all of these states.   
 Also, we have prevention resource centers. You've heard of some, like Special Olympics and the MPD Coalition. I was also asked to think about how we can integrate what our states do with what these prevention, public health prevention resource centers do. Those are the questions I was asked to think about. What I did was I threw some other things in there also, as you will see during the course of the presentation.   
 So what do we know? If you go on to DHDS, you will know what people with disabilities are underserved in terms of their health. They're more likely to have behavioral risks, be obese, smoke cigarettes, be physically inactive. They're less likely to receive services like oral healthcare. Those visits are problematic especially for those with intellectual disability, and less likely to get mammograms, women 40 and over less likely to receive mammograms. That's what our website tells you at a state level. There are these gaps or disparities in health.   
 The question I have is are these generalizable? These findings that we see from a state level data, is it applicable to people with limb loss, intellectual disability and paralysis? The problem is we do not know about it at the population level. That's one of the problems we face here.   
 So that's challenging for me, because with the various programs, particularly at CCD, cancer program, smoking and health, I talk about people with disabilities and they always ask me, Who are you talking about? OK, so you work at Special Olympics, are you talking about people with intellectual disability, paralysis, limb loss? I'm like yes, but I just catch it when it happens. That's the problem that I have. The problem is what I have is not intuitive; I can't relate to any of these populations. That's a difficult sale, even within CCD.   
 So the problems, what we have with this data, this data are you limited in any way in using special equipment? I have like a 40,000‑feet view. Flying over, looking out of the airplane, I can see it is white, I think there's snow on the ground, or green, there's grass, or yellow, I can't tell if it's wheat or what, but I have that type of view with these systems, these data that we have.   
 With the ACS questions that both Debra and Matt talked about, I think that those will get us a 30,000‑foot view, but it's still problematic. It's still not rich enough to be able to articulate what these populations need.   
 So also, the challenges are many people in living conditions may not identify with disability. So when I get up and talk about disability, and folks from the hearing impaired community sometimes object; they don't see themselves as having a disability. So that's another challenge that we have in health.   
 We have a small budget, challenge for many of us. And access. This is one of my pet peeves. When you don't know what to do, you start talking about access, personal opinion. It's the belief here is that if you improve access it will float all boats. I guess the point I continue to make to my colleagues is that's a problem. When you don't define the population, you can't figure out where the waterline is, so you can't really say all boats are going to float.   
 In terms of solving this, I'm an economist, I started thinking, well, it needs a dollar component. I'm an economist, so it's about costs, even though costs is a little of what economists do. It all boils down to the dollar, as you know. I'm really going to talk about populations and diagnoses.   
 I need to integrate states, our states, resource centers, especially, the coalition at a population level. We need to be talking about population level. That's how I have to think about this problem.   
 In terms of defining value, I defined that at the intersection of cost and quality. It's the cost incurred and value here. Off our defined populations, I'm thinking about three. Particularly the fourth population. ID, intellectual disability, LL, limb loss, DS, paralysis. I'm going to throw spina bifida, which can be a subset of paralysis, in there.   
 OK. I'm going to focus on Medicaid. That's what I decided for a few reasons. Each state has its own claims data. It's a big program. The claims data will give us the dollars and diagnosis. These are a population that is disproportionately poor, many have disabilities. What do I mean, many have disabilities? Well, this is some data taken off the Medical Statistical Information System, off the web. Basically CMS data off the web. These are four of our state programs here: Illinois, Montana, New York, South Carolina. I'm going ‑‑ you can do this for many states. I think all states, most states for 2010. I'm going to focus in on New York here. What this data appears to say is, for New York, in the Medicaid program you've got about 5 million people who are recipients. The numbers whose basis of eligibility is disability is about 735,000. So basis of that is building disability and Medicaid program in New York, about 15% of people in the program are in the program because of a disability.   
 So if you look at the expenditures then, the expenditures for the New York program are $42 billion a year. $42.7, $43 billion. The disabilities expenditures are 20 billion. 15% of the people account for almost half of the expenditures. That's true in many states. If you look at just the selected states there, Illinois, 12% of the population accounts for about 42% of the expenditures. Folks with disabilities are consuming lots of healthcare, Medicaid. I really want to figure out what that looks like.   
 So I've kind of ‑‑ as an economist, I'm playing with numbers. I'm just playing with the New York numbers that I have. So total number approximately 5 million, total expenditures 42 billion, average cost about 8,000 per recipient. When I look at the average cost for folks whose basis of eligibility is disability, it's about $27,000. I've gotten some supplemental information to look at ID. I am somewhat confident in the numbers I'm getting, but not confident enough to give you a precise number. The average cost is $100,000 plus.   
 I've talked to a couple of Medicaid directors, they say, yeah, that's in the ballpark. So the average cost for ID is $100,000 plus. If you think you know a little about this population, so what do I want to know? Well, before I get to what I want to know, I want to talk about money's worth, being an economist. The average cost of Medicaid disability is 100,000 plus. We have this terrific CCD program; it's a $200 million program, I think it's got an increase in budget. And that's about 400,000 women each year; it has them screened. If they're unfortunate enough to have cancer, Medicaid kicks in, covers the cost of treatment.   
 So the average cost for identification screening is about $500. In terms of our disability and health program, it's less than $5 million to describe some number of people, hopefully with ID, limb loss and paralysis, and now it improves the quality of their care.   
 Again, if we can do this, so our partner state receives $300,000, it identifies 30,000 people with ID, that's a tremendous value in my book.   
 That's how I get about this.   
 What are the needs? What am I trying to fill in? This is what I hope to fill in. If you look at those columns: Medicaid program number, demographics, age, gender, race, healthcare statistics, mammograms, oral health, hypertension, behavioral risk.   
 Some of the work I'm doing, I'm looking at the initiative, one of the things is hypertension. So if you look at people with hypertension that are treated but uncontrolled, there's 15 million people in the US who have treated hypertension that's uncontrolled; 10 million, 2/3, have a disability. These are the things I want to look at, the Medicaid, but not in general. I want to look within these ID, limb loss and paralysis populations, then a total at the end. I want to be able to fill in those blanks.   
 We don't know this number. Then, say for the limb loss example, I would like to know, well, is there a co‑existing condition? Is your limb loss related to something, say, like diabetes? If yes, what's the diabetes? Are you getting good quality of care? Can you ascertain if the limb loss is due to diabetes? These are the types of questions I would like to answer.   
 The benefits of what I'm proposing integrates what our states do with resource centers like Special Olympics, MBT Coalition. It's data driven. You can get cost estimates and do money's worth analyses. I think it can help reduce the disability casualty issue. If you're obese, and you have an intellectual disability, we know that it's not the obesity causing disabilities.   
 Financially populations over time, within my unit, CCD, we have a hearing group, early hearing intervention group, visually impaired, children with disabilities. We have a CDS group. I think we can also with the Medicaid data look at these different type of populations perhaps at the time.   
 One of the things here, it won't be able to make groups if we use diagnosis that don't see themselves as having disability. Some, I guess, might be in terms of the social model of disability, but again I'm interested in folks with ID and muscle paralysis. Keep that in mind.   
 Nothing about us without us. I hear it all the time. It's important to have people with disabilities represented in different committees. I agree with that. I've always wondered can I have people with intellectual disabilities on the committee? I'm curious. Does anyone have an answer? My guess is very few.   
 Again, not trying to be provocative. These are just questions I'm interested in answering.   
 I think the approach that I'm kind of thinking about has a number of benefits. We asked a number of questions. What do you believe covers the disability? Does Medicaid cover it? That's more challenging. Lots of times when someone has a basis of eligibility disability, those records are not kept, so they're in Medicaid for seven years and no one can tell you what got them in in the first place. Then you have to start to look at the diagnosis to figure out what got them in. It's a guessing game. What are the costs associated with the leading causes of disability? Top 10 for Medicaid. I'd love to know. What are the hospitalization rates? What are the leading causes of use among people with intellectual disability? I hear in one state, Delaware, where Medicaid doesn't cover oral healthcare of people with intellectual disability it's treating in emergency rooms, that's where they get their oral healthcare. There might be a cost argument perhaps one can make, that again Medicaid should cover oral healthcare for people with intellectual disabilities.   
 These are the things that I hope to flesh out and think about in the future.   
 In summary, few understand what I do.   
[Laughter]  
It's not integrated. There's no list of defined population. When I talk about disability, I think about it in terms of social model, are you limited in using special equipment? Nobody knows who the heck I'm talking about. So the definition's too broad.   
 We lack the disability conditions specific data and program efforts. I think the solution focuses on three populations I mentioned, also spina bifida, would help us to find value in the statement.   
 A lot of it integrates what states do with our resource centers. It's population and evidence based. It has the evidence the physicians, policymakers often want. Also has the ability to integrate across various CCD teams and programs. It includes people with disabilities. I can actually be specific.   
 Again, there's my contact information. My name is Brian Armour. I'd love to hear your thoughts on this. If you want to get it later. I'd love to hear your reaction. Again, there's a disclaimer here: This is me talking, not CCD.   
 Thank you so much.   
[Applause]  
>> Debra Brucker: Thank you, Brian. We now have Terry McMenamin. Then, following that, I believe we have a replacement for Jennifer Sheehy. Is someone ‑‑   
>> Yes, I'm here.

>> Debra Brucker: Charise Hunter. She will be after you.

>> Terrence McMenamin: We'll probably leave extra time for questions, which I will probably confuse everyone and you'll have questions. Hi, I'm Terry. I'm also, along with Brian and Matt, one of those guys who shows up every year. You may know me.   
 I'm from the Bureau of Labor Statistics, and I guess about five years ago we added some questions to hopefully identify most people with disabilities. We had the same six questions as in the American Community Survey, several other surveys using those questions now.   
 We work closely with the Office of Disability Employment Programs to get these questions in, and to continue to. The Office of Disability Program Policy funds the questions in a lot of the work that we do.   
 These six questions, we want to identify people with disabilities. They went in June 2008. We were able to start releasing data in 2009. The data back to June 2008 are available now.   
 We have our data release monthly, and that includes all disability data. So data by sex, race, ethnicity, all employment, on employment, not in the labor force and so forth. All those categories are now available by disability. All of the data being shown today, they're all available on a monthly basis and have been back to June 2008.   
 Disability in noninstitutional basis, what we focus on in the CPS, and that includes all those who aren't in institutions, such as correctional facilities and residential nursing, mental health healthcare facility. I tried to narrow that down to exactly what that means a few years ago, and essentially what it means is if you can walk out on your own and come back, you're in the CPS. If you are not allowed to leave without supervision or someone's permission, then that group of people would not be included. If you're in the armed forces, we don't ask you if you're employed.   
 Here are disability rates by age, the annual data from 2012. So as you see here, a large portion of those are 75 and over have a disability, and much less for those 16‑24 and younger ages.   
 This is something to keep in mind, as you will see, as you can see here ‑‑ well, everything kind of fades in there. A much larger portion of people with disabilities are 65 and over, 45.7% of that group, compared to 13.5%. That has a large impact on whether people participate in labor force. As we all know, 65 is the age we all want to retire, down to the Bahamas or whatever, in this country. At the age 65, people just naturally participate in labor force a lot less.   
 So a group like people with disabilities, that generally have a much higher portion who are that age or above, you're going to see naturally a much lower labor force participation rate. So we try to ‑‑ essentially, our tables try to include, for the most part, an age break that's not in any of our other tables on a regular basis, those 16‑64. I mismarked this. This table here. I apologize. I was going to rush in the last two weeks. The bottom line should say with a disability, 65 and older. This is the number of people as measured by the CPS on a monthly basis of persons with a disability, which is the lower line; person with no disability, which is the red line in the middle, then the total overall. It's interesting to me, as the baby‑boomers start to enter this 65 and over group, you can see a marked increase arise in the total of persons with no disabilities, but persons with a disability clearly is fairly flat. Even a slight rise, it starts there, kind of flattens out. As the baby‑boomers start adding to those 65 and over, as of yet it hasn't shown a marked effect on those with a disability. That will be an interesting thing to watch as we see those people, the baby‑boomers, flood into this age category.   
 Labor force participation rates, I was mentioning before, that's the portion of the population that participate in labor force. Now, labor force includes people who are working and people who are considered unemployed. That would be people who are available for a job, they want a job and have been looking for a job actively the four weeks preceding the survey.   
 The sum of those two groups is labor force, and as you can see the lower lines, which are supposed to be blue, and the higher lines, which are red, the red lines are those with no disability, blue lines are those with a disability. We've, since we started measuring this on a monthly basis we've seen a consistent, much lower labor force participation rate for those with a disability. This is something that, among all the different characteristics that we measure in the CPS, we've never seen that type of characterization before.   
 So when we started measuring this group, that was something that really jumped out at us. As I mentioned before, it's something that clearly is something you would expect when a much larger group of persons of that characteristic are age 65 and over.   
 As I said, we try to break these data down by 64 ‑‑ 60‑64 and 65 and over. As you can see, even among those 60‑64, the labor force participation rate is consistently much lower than those with no disabilities.   
 Here's monthly data. You saw some earlier, the opening presentation. Here is persons with a disability, by sex and 60‑64. As you can see, since June 2008, which was already into the recession, these lines have moved fairly closely together.   
 The overall rate of workforce participation has done about the same. It's been consistently dropping, and that's something that we haven't pointed to a reason for, but it's certainly something that people who study employment and so forth are concerned about.   
 Now, employment population ratios are simply those who are working divided by the total of that population, and as you can see this is much the same. You can see across race and ethnicity that's a fairly consistent story, that the employment population ratios are significantly lower for those with a disability than with no disability.   
 The employment population ratios by educational attainment shows the same story. There are a couple of interesting things here that I'd like to point out. One is that only 28.4% of people with disabilities who have completed a four‑year degree or higher are employed. That's puzzling.   
 The good news here is that, as you can see on this chart, much like those with no disability persons with a disability their employment population ratio has climbed with their higher levels of education.   
 Employed persons by occupation, you saw that on Matt's presentation. You can clearly see the management professional categories, which are these are very large occupational categories. Management professional categories clearly show a higher portion of persons with no disabilities amongst that group employed in those categories, compared to those with a disability. And those with a disability, a higher portion of persons employed are employed in the service and production occupations than those with no disabilities.   
 Here's the percent distribution of employed persons by class of worker, and this shows in the government class the numbers are fairly close; persons with a disability and persons with no disability are equally likely to work in government.   
 In private wage and salary occupations, the persons with no disability are more likely to be employed in those groups. Persons with a disability are more likely to be self‑employed.   
 Now, I'm not providing too many reasons here. That's something that BLS we tend to try to let the numbers speak for themselves. So as far as providing purpose and reason and so forth behind numbers, we leave that to other people as much as we can. But as you'll see, we do try to delve into some of the issues that, for example, have been brought up today. I'll get into that a little bit later. But I thought I'd give that disclaimer here.   
 We do look at also, within our survey, the persons who work part time for economic reasons. And to give a brief explanation of that, that's people who usually work part time, so their hours are below 35 hours, usually, per week. We ask them the reason that they work part time, usually. When people say that they would prefer to have full‑time hours, but they can only get part‑time hours, for reasons such as their hours were cut back or they can't find full‑time work, we call those reasons economic reasons. So it's essentially beyond their ‑‑ out of their own influence to get full‑time hours.   
 So you can see here, those with a disability show a slightly higher rate of working part time for economic reasons, among those who usually work part time.   
 Unemployment rates: We have a number that many of you should be fairly familiar with. The official unemployment rate comes out the first Friday of every month. In that news release that we put out, the sixth table on the news release focuses on those with a disability. Now, these are annual numbers here. The monthly numbers are something, as I said, comes out in the same press release as the official unemployment rate. The unemployment rate is consistently higher for those with a disability throughout the time that we've been collecting these data.   
 An interesting thing you will see, among those age 65 and over the unemployment rates are consistently much lower than amongst those 60‑64, and as we discussed before the reasons for that are the high rate of unemployment ‑‑ or retirement and so forth, those types of reasons that go into being 65 and over.   
 Now, amongst those who are not employed or unemployed, if you consider that group to be not in the labor force, now, we do ask some questions of those not in the labor force to try to clarify how much of what we might call an attachment to labor force they have. For example, we ask persons if they want a job. This chart breaks down people who said that they did want a job, by disability as well as reasons of discouragement. Because we asked that additional question, if they say they do want a job, what the reasons are that they feel they haven't been able to find a job.   
 Now, this chart also breaks down these groups by 60‑64 and 65 and over. As you can see, a very small portion of those not in the labor force say they do want a job in the first place. For those with no disability, it's around 5%. For persons with disability it's just under 2%. That's for persons 60‑64. For those 65 and over it's around 1% or less for both groups.   
 Now, as I said, these are broken down further into those with discouragement and reasons of discouragement included, for those with no disability 60‑64, a little less than 2%, and it's around 1% for those with disabilities 60‑64.   
 This points to, these data, we didn't collect these data specifically to address the idea of persons with disabilities desiring to work or so forth, but clearly these speak to that theory, the idea that people with disabilities want to work a lot more than they currently do. Clearly, unfortunately, the data show that if you ask people with disabilities, "Do you want to work?," it's a clear result.   
 I'm not saying that the people with disabilities do not want to work. I'm saying that sometimes when we focus on the employer and try to change their attitude towards people with disabilities and increase employment that way, that maybe the lack of results there may be because we're focusing on the wrong end of the issue.   
 Now, we have in the CPS, since it is a monthly survey, we have the ability to add supplemental questions to the end of the survey on a monthly basis.   
 In May 2012, we did just that with disability questions. The supplements themselves follow the regular CPS questions. They can be linked to the questions that we asked earlier in the survey. So any categories, such as disability, age, employment status, those types of things can be a link to a specific question.   
 So we put a lot of work into, along with ODEP and other groups, putting together a set of questions that can be linked to and address issues that we found, such as desire to work or things like that, to say add to the information or clarify some of the information that we get in the regular CPS.   
 These supplements have to be planned and funded years in advance. As I pointed out, the ODEP group and other people work on this for several years before the supplement went into the CPS.   
 Questions are subject to a very detailed testing and approval process, and in May 2012 we added this supplement. We asked questions about, and I'm going to read through these quickly, barriers to employment, prior work experience, career assistance programs, participation in those, participation in financial assistance programs, difficulty completing work duties, requests of changes in the workplace, commute to work, work at home, flexible workhours, and temporary jobs.   
 Now, these questions, several of them, included follow‑up questions. For example, participation in financial assistance programs was followed up by a question involving the likelihood of working if there were no limitation combined with that financial assistance program.   
 Just to show you a couple of slides of data from these supplemental questions, this first chart shows persons with a disability who are not employed, who reported having a barrier to employment.   
 Now, we didn't specifically limit persons to one barrier. People were asked about each of these barriers in order, and were able to say yes to each of them. Clearly, right around 10% or less reported lack of job counseling, lack of education or training, lack of transportation, loss of government assistance, need for special features and employee or co‑worker attitudes.   
 80‑81% reported that their own disability was a barrier to employment.   
 Another question we asked involved persons with disabilities and their receipt of career assistance, and we broke this down by employment status. We found that persons who were unemployed were ‑‑ a very large portion compared to the others, had received career assistance, a little over 25%. Those who were employed reported that they had received career assistance. This is within the past five years that we asked about this. Around 12%. Those not in the labor force were the least likely to have received career assistance, just over 5%.   
 Now, here are some links for the CPS data. We had a ‑‑ we have the disability news release. It's an annual product, and I guess the annual disability news release. I'm sorry, it's the second link, the May 2012 disability news release, which is the first link, that's the one that involves all the supplemental questions.   
 The third link is the monthly employment data. Table A‑6 again focuses on disabilities data.   
 Recently, there was a visual essay in our monthly Labor Review magazine, the link there. Then disability frequently asked questions about the CPS data are the final link.   
 My contact information is on this last slide. I encourage you to contact me if anyone wants to talk about any of these data too. Thanks.   
[Applause]  
>> Hi. I'm Charise Hunter with the Department of Labor's Office of Disability Employment Policy, here for Jennifer Sheehy. I was going to speak a little bit about the tabulation mentioned earlier by Matthew, from the Census. Since it was mentioned, I wanted to add and emphasize that we really do encourage the use of that tabulation. It has one billion, that's billion with a b, estimates of disability status and labor force participation for individuals with disabilities ages 16 and over.   
 So we're very proud of our relationship with BLS to be responsible for the CPS disability data, and our relationship with Census and the federal compliance, contract compliance office.   
 I wanted to add that and really emphasize, if you do use it, we also would love to know about it. We have a central contact at ODEP, Dillon Orr. Reach him at orr.dol.gov, who coordinates the work with the Census Bureau. So please let us know if you do use this information.   
>> Debra Brucker: So thank you to all of our data people. Everyone take a deep breath. I know that was a lot of information in a short amount of time. But any statistics need context and need continual evaluation. We're counting on you to keep us honest and keep pushing for better statistics.   
 I wanted to open it up for questions from the audience, for any of the presentations that happened this morning. I'll bring the mic over.   
>> That's all right. The gentleman who just spoke ‑‑

>> Debra Brucker: Since we're webcasting it, it would be helpful.   
>> The gentleman who just spoke, with the Bureau of Labor Statistics, why are the people that are institutionalized left out of the numbers? Probably a very stupid question. I just don't know the answer to it.

>> Matthew Brault: So, the civilian noninstitutionalized population is the typical survey frame for most federal surveys, unless the survey specifically is targeting a particular population. So you find that same civilian noninstitutionalized population used for the survey in program participation, the national interview survey.

The ACS is a little bit different. It actually goes to the larger population, but because of that there are, I'm going to say, more expensive efforts to reach those populations. So to get to survey people in prisons you need memorandums of understanding with the federal, state, and local jails, state prisons, federal detention centers; getting access to people in nursing homes is not always easy due to working with HIPAA information. There are a lot of other barriers to just data collection involving people who are institutionalized.   
 Probably the other side of it is, for a lot of data applications people are trying to apply these things to situations of people who are in the community, living in ‑‑ using transportation services, using local business services, and in that sense the civilian noninstitutionalized population tends to be the group who are actually in the community and using local services.   
>> Thank you.   
>> I don't know to whom this goes, but many of us struggle to kind of understand the trajectory of disability over the next 30 or 40 years. And we as novices often take the data that you gather and sort of project age cohorts into the future. Because we're novices I'm not sure we do that well, and I'm wondering whether there are efforts among your agencies to really look at that. The trajectories we see right now, your graphs are so gentle, disability basically staying the same within the US population. We know that's going to change dramatically over the next 30 years. I'm wondering if some of you with more sophistication are kind of approaching this either as total numbers of people with disabilities, persons with, say, self‑care needs as a proportion of the working‑age population, just things to help us understand what we're going to struggle with as a nation as we kind of meet the needs of people with disabilities.

>> Matthew Brault: I think I have two responses to that. One is the Census Bureau does do some projection work. They have not tried to do projecting of disability as a topic. I don't know if that's to say they won't do it in the future. I think it's currently something that's not on their agenda, but it's not my own expertise. It's not in the area of projections. But that's not to say we couldn't figure out something moving forward.   
 The second side of things, one of the things we do know is that within each age group disability was actually ‑‑ has been going down. So if you look at the disability rate amongst, let's say, 65 to 70‑year‑olds, the disability rate actually was lower in 2010 than it was in 2005. But what we actually see is that the decrease in each individual age group has been offset by the fact that the baby‑boom population is aging into higher risk groups. That number, when you say disability rate is staying the same, that really is I think masking something that's going on with disability on the individual age level.   
 So I think that this is a push also for showing some things as age adjusted or age standardized estimates of disability. That might be also a useful statistic kind of moving forward, and that's something that I know the Census Bureau is looking to start providing in addition to whenever we produce a "proved" disability rate, but that's sometimes in addition to having an unadjusted statistic, to have an adjusted statistic. We added that to the Americans with Disability 2010 report.   
 The other thing that I think in order to do good projections in the future, we need to have better information about disability status longitudinally over the long term. I don't think there are any studies right now that really have examined the life course of people with disabilities over a 10, 20, 30‑year period. I don't know of any source where that really you can get that information now, and the downside of that is if we were to start something right now we wouldn't get the information for 25 years or so.   
[Laughter]  
So the ‑‑ I think there is a definite need for some longitudinal analysis. Maybe the cohort‑based studies is what we have, but ‑‑ yeah.

>> Terrence McMenamin: One thing quick about BLS data. We try not to project, as much as possible. Like I said, we try to let the data speak for themselves. We do have an Office of Projections, and I highly doubt they'll have anything disability‑specific, but disability rates and likelihoods and so forth are included in the projections. And I would encourage you to take a look if you're interested in employment, to take a look at their website in the BLS website just to see how those types of things are included. Obviously, the baby‑boomers are going to have a big effect on the labor force participation rate, which we already kind of pointed out a little bit in my presentation. Quite simply, the employment projections office are the ones to talk to about that.

>> Brian Armour: As an economist, I'm really interested in forecasting, and we do it often. We usually do it wrong.   
[Laughter]  
But I will say this, in terms of I think that it's defined population, so when you want a number like disability I think you really have to define your population. So I believe with Social Security, DEI, given issues around trust fund solvency, I'm pretty sure that Social Security Administration forecasts the DI population, and I believe they forecast up to 75 years out. If someone from Social Security is here, maybe they can answer the question for you. I'm pretty sure that information you're looking for exists for SSDI. I would be happy to try to help you find it.   
>> My question is for Terrence. I was very interested in the slide that you had about the rates of persons not in the labor force currently who want a job, and it seemed interesting to me, not just the 2% statistic for persons with disabilities, but actually the 5% statistic for persons without a disability. To me that just seems low, given all the people that we happen to know are out there currently looking for work who don't have it. So I guess I'm curious how the question was asked or if you had any thoughts about why those rates are so low, both for persons with disabilities and for persons with no disability.

>> Terrence McMenamin: Hi. Good question. Unfortunately, like I said earlier, we try not to get into reasons behind the data. We try to let the data kind of speak for themselves. It's been pretty consistent over time that generally when you see, when we ask people about ‑‑ who are not in the labor force what we call their attachment to the labor force, what we do is focus on the first ‑‑ we ask them whether they want a job. We ask people who say that they do want a job, they're available for a job, but they haven't looked for a job within the last four weeks, that last part would be the reason that they wouldn't be included as unemployed.   
 We ask the affirmative question, say, Well, have you looked for work within the last year? We do have varying levels of looking at those who are not in the labor force and what their attachment might be, and so forth. It's been pretty consistent story that most people not in the labor force generally have a small portion of them are looking for a job, available for a job or have looked in the last year. We, like I said, we don't try to hypothesize what the reason behind that might be, but it's something that's been pretty consistent over time.   
>> That holds true even during periods of high unemployment?

>> Terrence McMenamin: Yeah, you will see movement up and down with that. So for example, portion 60‑64 shown here of persons with no disability it's around 5% that report that they want a job. Maybe you go back to 2007, before we really saw the recession kick in, that might have been down closer to 3%. But even so, still a very small portion of that group who are not in the labor force.   
 So right now, people are generally still struggling to find jobs. At least, that's what we understand to be the case, and it's around 5%. That's pretty much a height of that. So think about it that way, when things were better you see a lower number.   
>> I just have a follow‑up on that slide as well. So for both persons with disabilities and persons without disabilities, is there an initial measure whether they had ever participated in the labor force?

>> Terrence McMenamin: We don't have a question like that in the survey. We did ask a question like that in the supplement, and unfortunately we only asked that question of people with a disability.   
 We really regret now, in hindsight, not having asked that of everyone. We did ask that question of people not in the labor force with a disability. And an additional problem with that question was that we were unable to establish the onset of a disability. So to compare, to take a look at that for people whose onset was far in the past or recent, it's difficult to say, all right, Did you used to work before you had a disability or have you worked since? But we did ask that question in the supplement. So the supplemental questions we have that information for persons with disabilities.   
 The one thing I'll say about it is that it shows that among ‑‑ the higher the age of the person, the more likely that it was that they had worked in the past. So in reality it kind of, the amount of information that that question added to what we know is very minimal. The older you are, the more likely you worked at some point in your life, because at 65 you're much more likely to have had time to work at some point in those 65 years than someone who is 24 and has spent most of their life in school. So certainly, you can take a look at those, that information. I believe the fifth table in the press release, the supplemental press release that has information on that.   
>> Could I also ask a follow‑up on that? Then I have a Medicaid question to ask on utilization data.   
 Can you remind me, I'm sorry if you said this, who exactly is surveyed, what are the ends, how many people, and what is the response rate? You talked about being able to survey people monthly. Are you surveying the same people monthly, or are you surveying different people? Sorry if ‑‑

>> Terrence McMenamin: I didn't really go into the details on that. The CPS is a monthly survey of 60,000 households, about 60,000 households nationally.   
 We have a rotational, essentially each household is in the survey for eight total months. Your initial four months are four consecutive months, then that household is not surveyed for eight months, then they're surveyed for another four months. Each month you advance along that, the monthly survey. So each month we have 1/4 of the surveys is new to the survey. They may be reentering the survey or entering the survey for the first time.   
 So long story short, we don't interview the exact same households over a long‑term basis. We do have a fresh set of households every month, and some of those are reentering after having been out of the survey for eight months, some of those are brand‑new households.   
 Does that answer your question? It's a little confusing ‑‑   
>> It's a random 60,000 households? They're selected?

>> Terrence McMenamin: Right.   
>> That's helpful. Thank you. Then I had a question about your data, that you had said that you use state claims data to derive disabling condition. Is that right?

>> Brian Armour: No, I took information off the internet for the disability information of the Medicaid Statistical Information System. But also when your compendium, there's medical data in the compendium, in the booklet, and they were used in a different source. Well, similar source but slightly different time period, and the numbers are basically identical for people with disabilities. They're a little different for Medicaid population in general.   
 If you look within the compendium, you can find the information. But the exact information I used, I can provide you the website link to it, if that's what you need.   
>> The reason why I'm asking is because it's really difficult to rely on a claim to provide you with the information about a disability, particularly for people with IDD, because those IC‑9 claims do not land on a claim. The easiest is the home or community‑based waiver populations, so the other folks on Medicaid that may not be in a waiver, so that, just to qualify that $100,000 figure, that may be a subset of the population and it may be the high‑cost one. So it could be skewing the data.

>> Brian Armour: I agree with you. We don't know. To your point, why claims data, I also agree that it's not ideal to use diagnosis to figure out who has ID. I much prefer to use the basis of eligibility, what gets you into Medicaid. If disability is your basis of eligibility and ID is the primary disabling condition that qualifies you for your basis in order to be insured under Medicaid, that would be ideal.   
 What I did, we're doing a pilot project to see if we can figure this out, and the pilot project I made the comment where I discovered that in one state, I won't name the state right now because the work is ongoing, what we figured out was that if disability ‑‑ I was talking to physician qualified folks for Medicaid disability, it's his determination qualifies folks, and then that record disappears and you're in for seven years. It was impossible to go back and figure out what got people in, hence we're using diagnosis codes and it's not ideal.   
 Hopefully one of the policy changes, at least within that state, is when you qualify someone where their basis of eligibility is disability please keep that information on file or somewhere so folks like me can go back and figure out what was the primary disabling condition and all of the conditions that qualified you.   
>> Having come from a Medicaid program, it's either disability yes, disability no, not what type of disability. Now, it would be ideal if that were the case, and then oftentimes the eligibility system doesn't talk to the claims system. There's just no way to cross‑block. Maybe in the future that is something ‑‑

>> Brian Armour: No, it's not easy. The physician I talked to, when I asked about ID specifically, he talked about IQ, often used in defining ID, he basically said if your IQ is above this stage threshold, and you clearly need it to be insured, he would figure out how to qualify you based on some other criteria. I think there's no real easy answer to the question you're asking, and that's what we do. We make compromises all the time. You're asking a great question, which ‑‑   
>> When I heard that, I thought ‑‑

>> Brian Armour: What we're doing is reaching out to our resource centers and asking Special O and Arc to help us define people with ID. So it's not us doing it, it's folks that actually work with folks in ID that are doing it. I feel a little bitter ‑‑ a little better about that, but again, it's not ‑‑   
>> Bitter too, probably.   
[Laughter]  
>> Brian Armour: Again, it's not ideal. I get your point. Thank you.   
>> Terry, I'm curious, going back to your chart there, I was thinking that the question regarding discouraged workers was only asked of people who had ‑‑ I didn't realize it was asked of all people not in the labor force. Is that correct? I thought it was limited to only people who had not been in ‑‑ or had been in the labor force in the past 12 months, something like that.

>> Terrence McMenamin: Persons who haven't looked for work in the last four weeks, but have in the last 12 months. We asked why they stopped looking for work.   
>> OK. This wouldn't include people who had been not employed or only includes people who have ‑‑ long‑term discouraged workers wouldn't necessarily show up on this?

>> Terrence McMenamin: If someone stopped looking for work over 12 months ago ‑‑   
>> Right, they wouldn't have been asked.

>> Terrence McMenamin: Right.   
>> OK. One of my thoughts in terms of people with disabilities that may have gotten discouraged longer ago than that, therefore they're not ‑‑

>> Terrence McMenamin: People 10 years ago, pick them up.   
>> Right. I was curious about that. OK. Thanks. Actually, Matt, I also had a question, maybe more for Charice, the tables that you developed, they're based on 2008‑2012 data. I wonder, is there plans to update them to more current data at some point?

>> Matthew Brault: 2008‑2010, three‑year data. It's the matter that the money has to be there. I think that's just it.   
>> At this point, it's that's the years ‑‑   
>> We can do that.   
>> OK. Thank you.   
>> Thank you. I wanted to follow up on the projection question. Really, thinking about this at the community or county or state level, where the barrier of 64 or, not or employment policy, may not be as important as mobility and need for services and concerns about isolation in suburbs and other kind of things that clearly we can see happening. I know a number of communities are looking at the questions of the implications physically and programatically in terms of aging population.   
 So there must be more around in terms of those kinds of projections or those kinds of thinking, than something as specific as trying to project a particular health condition, which sounded like part of the response. Mobility itself is pretty correlated to age.

>> Matthew Brault: Yeah, so the American Community Survey actually does have a question on difficulty walking and climbing stairs. Which can add a large component to mobility. With the five‑year data coming out next week, we'll be able to get that at the very localized geographic area.   
 I think in terms of projecting that information forward for small areas, you need to have multiple points of time to begin with. This is really one of the first times we're going to have that information. I think that there are a lot of factors going into trying to build a good projection model, and I think that if we just start assuming that the rate of disability at a certain age is going to stay the same, I think they're highly correlated. But there's highly correlated and then what the actual level that people at different ages experience mobility restrictions or mobility limitations; if that changes over time then that's going to change the projections.   
 In addition to just the changing of the aging of the population, which is relatively easy to adjust for because it's births and migrations, effectively, births, deaths and migrations. So I think that it would be possible. I think we just have to know, get a better idea what we think is going to be happening, then essentially being more explicit, I guess, with some of the assumptions we used.   
 I think it's a worthwhile task for someone to undertake. Again, I don't know if this is something for National Statistical Health Statistics, or the Census Bureau, or BLS, CCD or who should take the lead on it, but yeah.   
>> Thank you. Because it seemed important, at least in terms of local planning, and sometimes I think disability statistics as a field has kind of, in terms of trying to be precise or trying to fix exact measures, a lot of people out there also a lot broader questions.

>> Matthew Brault: Yeah.   
>> I don't know what the allowable variance is for really getting somebody to see the world is changing, but there must be some language for that.   
[Laughter]  
>> Matthew Brault: Yeah. The other side of that, I'll mention this, the allowable variance, I guess, for the small areas we see something like we do see a lot of variation from one year to the next, potentially, in statistics, especially in small areas. And we know some of that's just sampling. It's the effect of sampling.   
 When you're trying to build something that's going to look what is a trend going on and the data is looking like this, it's just this up and down, bouncing back and forth, it's hard to really say what's going on, and that's got to make trying to project that information going forward even harder.   
>> I don't want to belabor the point on that 5% again, but some of my personal experience of working with people mainly with intellectual disabilities, a job and issues around those lines, their biggest fear, one of the calculations that we had to sit and do is if I do take this job, whether part time or full time, how does that affect my benefits? I think we originally started out about that mindset of graduating people from schools that then they're taught how to apply for benefits.   
 The biggest fear that the population I was dealing with is if they go over that number they're going to lose their benefits, then if they lose that job they're at least six months, nine months, a year possibly without anything coming in. So I don't know how that affects that area, but that's kind of an observation I have on that.

>> Terrence McMenamin: I am very familiar with that, with that type of scenario. A lot of people that I've encountered in these meetings and others have a lot of experience with people who tie their likelihood of working into whether they lose their benefits or not.   
 As I said, that's something that we attempted to try to put some kind of number to with the supplement that we did in May. As I said, we asked a question about receiving assistance, and we asked about specific types of assistance, and then we asked the follow‑up question about whether the idea that you might lose that assistance if you started working affected your either likelihood of working at all or increasing your hours.   
 So there's some data there that tries to quantify the scenario you're describing there. But as far as talking to persons not in the labor force, persons in the labor force and unemployed, so forth, these data can only really measure directly whether you're working or not working and whether you're looking for work and want to work. Whether someone under the circumstances you're talking about they may ‑‑ the answer to that question would be complicated by the factors that are included in losing their assistance, and so forth.   
 So that type of thing would be very difficult to measure for people with disabilities in a way that when you say, "Do you want a job? Are you looking for a job?," those types of things, well, do they say yes or do they say no based on their perceived limitations that are tied in with their assistance and whether they'll lose that, how much they really rely on that in order to survive if they lose their job that goes away and then they have to reapply and take years to get it?   
 Like I said, it's just a difficult thing to measure. We did our best to try to measure that, or at least put some numbers to that in the supplement. So that might be something you take a look at there. We wouldn't, I wouldn't hold this number up and say, All right, this speaks directly to that type of circumstance.

>> Debra Brucker: Time for one last question before lunch.   
>> This is a question for Brian. You talked about value, it was the intersection of cost and quality. How did you quantify quality? Go into a little more detail about that.

>> Brian Armour: Yeah, I mean, that's a really good question. You know, in the past when I've been asked to answer that, I said it's like beauty is in the eye of the beholder.   
 I think in terms of healthcare, we know we have a few quality measures, like case sensitive conditions, UTIs. If you have good ambulatory care, it should reduce the need for hospitalization. Folks with spina bifida are being seen in emergency rooms and being hospitalized a lot for UTIs, then the urologists I work with who work with folks with spina bifida, it's an occupational failure.   
 Quality can't be defined, to answer your question, and I kind of got to it with diabetes, so one of the questions I have, if diabetes is linked to limb loss and we know we can look at the quality of diabetes care, I'm no physician, I'm told you can look at the quality of diabetes care with things like A1Cs, things of that nature.   
 There are process measures out there that we can use to kind of get equality, but something like, so a quality issue for me, something that I think it will be pretty intuitive for everyone in the room, if you're a woman with disability 40 years or older and haven't received a mammogram in the last two years, I think that's a quality issue.   
 Hopefully that answers your question.

>> Debra Brucker: Thank you, everyone, for your great questions this morning. Lunch is being served around the corner, so help yourselves. We will reconvene at 1:00 promptly. Thanks.   
[Applause]  
[Lunch break]

>> Colin Schwartz: OK, everyone, we'd like to get started. If you can make your way back to your seats.   
 So good afternoon, everybody. My name is Colin Schwartz. I'm the Manager for Policy and Communications at the American Association of People with Disabilities, or AAPD. I'm happy to help put on the third annual Research‑to‑Policy Roundtable with my colleagues from University of New Hampshire, Penny Gould and Deb Brucker.   
 Just housekeeping before we get started, there's a pair of glasses that was found in the men's restroom, at our registration table, in case anyone is missing their glasses. And please help yourselves to the food, we have lots of leftovers, and also to a copy of the compendium. You can access it online at compendium.org, and the USB drive as well, which we'll have copies from today as well as past compendiums.   
 So just want to give you a lay of the land for the afternoon. We'll have Dave Wittenburg speak to us from Mathematica on research for employment trends, and we'll focus on transition‑aged youth. Then we'll have an administration panel to talk about administration priorities and how we improve economic outcomes for people with disabilities.   
 To help kick us off this afternoon, please welcome our President and CEO, Mark Perriello from AAPD. I'll just do a short intro. As a political strategist, Mark Perriello oversaw highly successful efforts to elect candidates to office at the federal, state, and local level. And before joining AAPD Mr. Perriello served as White House liaison at the US Department of Interior. Please welcome Mr. Perriello.   
[Applause]  
>> Mark Perriello: Thank you, Colin. So welcome back, everyone. Welcome to everyone who is participating online as well. First, some thank yous. I had the chance to thank people this morning, but I think it's important for folks who are just joining us for the afternoon session that some folks get an important shoutout. First and foremost, everyone at UNH, Andrew Houtenville, Penny Gould and Deb Brucker. You all have done amazing work throughout the year to compile all of this data.

I want to thank the Kessler Foundation, specifically John O'Neill and his team for all of the work that they are doing, not only for today but so that we can continue this important discussion for the next five years into the future. Senator Hatch and his team as well. John Connelly, then the team at AAPD, Henry Claypool, who is our leader on everything policy as executive vice president. He just joined AAPD almost a year ago at this point from HHS where he was advising Secretary Sebelius on disability and other policies. He will be leading the panel discussion this afternoon. But thank also to Colin and Brianna for the work that you have done to bring all of this together. It takes a tremendous effort to actually find speakers, find rooms, put talking points together, press releases and all of that, and they really were the backbone from the AAPD perspective. So thank you all.   
 For this afternoon, we are, as Colin mentioned, going to talk about trends. So that is where we will start. I think it's an important discussion. As I mentioned this morning, there haven't been big surprises in these statistics, and my hope is that as we move forward, by "move forward" I mean we come together next year and come together the year after that, five years down the road, that we really have seen some great positive outcomes for people with disabilities and you get to start to talk about some surprises.   
 It's so important that the work that we do isn't just about the research, but that the research provides, right, the steppingstone, provides the information that we need to drive positive outcomes for the community.   
 So this afternoon, after we discuss trends, we will also have this panel discussion and the actual roundtable, where we look at, with leaders in the administration, how we drive outcomes for people with disabilities. From my perspective it's really going to take business, government, and the disability community working in tandem, working together in order to drive that change. It is not going to be easy. We all know it. The people sitting in this room, the people watching at home, you all know, right? The numbers aren't moving as fast as they should. Despite recent gains, we need to do more. So I have no doubt, with all of the smart people here, with all of the smart people we'll be hearing from this afternoon, that we will see some positive change, some positive outcomes in the future.   
 So with that, thank you all again for being here. Thank you to everyone who has put this together and made this discussion possible. I think I hand it back to you, Colin, to introduce the afternoon. No?

>> Colin Schwartz: Just pass it to Dave.

>> Mark Perriello: I will not hand it to Colin. Dave, thank you. Come up. I know it will be a very, very exciting conversation, especially for all of us data geeks out there. So thank you.   
[Laughter]  
>> David Wittenburg: I appreciate the intro. I love talking to data geeks. So hello. My name is Dave Wittenburg, I'm from Mathematica Policy Research. I'm really excited today to be talking with such a distinguished panel of disability experts, you can see the name tags here, they're not quite up here yet, and leaders from AAPD, the Administration for Community Living, NIDRR and the Department of Labor.   
 Last week, as there was a frenzy of holiday shopping, Henry, Sharon, Charlie, Jennifer and I got on the phone and met to discuss the roundtable. We came up with three goals for what people really want for the holidays out of this discussion.   
[Laughter]  
So those goals are, first of all, and you're going to hear the panels discuss each of these goals in hopefully a structured format in about 20 minutes, what are the agency priorities? What are you doing in 2013? That's the first issue.   
 Second, what do we know from the research that has been funded by these agencies?   
 And third, finally, what do we not know? Or perhaps what are we not implementing based on the research?   
 So you can think of my talk as really like a movie trailer. Like any good movie trailer, my main goal is to outline the general plot, which in this case are the statistics that might influence the policy decisions of agency leaders and maybe make you laugh or, sadly, cry.

With that intro, let me talk about the specific objectives of my talk; I have three. First, to motivate policy trends, which I will do using the statistics largely from the disability compendium that illustrate the employment and public trends of people with disabilities.   
 Second, I want to talk about the policy challenges facing each of the leaders that are going to be discussing later on today and reversing these employment trends.   
 And third, as a natural lead‑in to what's in the next panel, I want to give my own research perspective on the questions of what do we know and what don't we know.   
 So my goal really is to leave you with an overview of some of the challenges, to think about how difficult the challenge is facing the next panel and coming up with these innovative interventions to reverse the employment trends.   
 So let's start with the problem. So in this slide I show two employment trends from the current population survey shown from the compendium. Deb and Terry actually touched on these trends earlier in today's discussion.   
 They represent the employment‑to‑population ratio for those with and without work limitations. An advantage of this measure is that they're measured consistently over the CPS and represent an important subgroup to people with disabilities. But they only represent those who have a work limitation.   
 So the first trend shown in dark blue is the employment rates of those without work limitations. It generally moves up and down with the business cycle. But in 2012 the employment rate among people without a work limitation was 71%.   
 The second trend is the employment rates of those with work limitations, shown in the light blue, which I apologize is very hard to see on this screen.   
 But there are some fluctuations. This is the bottom line: Since 1999 there has been a steady downward trend. In 2012, the employment rate of people with work limitations was 14.5%. The challenge is the differential in the gray area, which is the difference between those with and without limitations. It's the employment gap that Deb talked about this morning.   
 In 2012, the gap in employment rates was 57 percentage points. By comparison, in 1980 the gap was 45 percentage points. In other words, this gray area, this gap in employment, has increased by 25% over time.   
 The second issue that I want to talk about, or second set of statistics, are around poverty and government spending. One notable trend is poverty. How are people faring with their income? As shown in the compendium, in 2011 the poverty rate was 31% for people with work limitations, compared to 12.4% for those without work limitations. In general, people with work limitations are more than twice as likely than those without limitations to be living in poverty.   
 The second bullet here represents changes in our government spending, which has been increasing substantially in recent years. So the point here is I want to illustrate that these trends have been going on, both the decline in employment, increase in poverty, even as we've been increasing government spending.   
 According to Stapleton and Livermore federal expenditures to support working age people with disabilities, which was estimated at 357 billion in 2008, accounted for 12% of all federal outlays, up 11.3% six years earlier.   
 The growth in the reliance of the working age population on disability benefits contributed substantially to the growth in expenditures, particularly in SSI, SSDI, Medicare and Medicaid. According to Andrew Houtenville and Deb Brucker, 65% of all working age people with disabilities receive benefits from at least one of 15 major programs, in comparison to 17% of those without disabilities.   
 What are the policy challenges? Well, one thing that I want to say, I think this relates to the secretary's innovation discussion that some of you might be attending later on this afternoon, is that these trends are not unique to the United States, and many have pointed to fundamental problems with the structure of disability support systems, such as the World Health Organization and World Bank.   
 What I'll show in the next three slides, I think the most common themes of these critiques, both for the US and abroad, are, first, providing supports to a diverse population who might face multiple employment barriers. Second, a fragmented disability system. And third, disincentives to work.

So let's talk about the first policy challenge facing our agency leaders. What I want to emphasize is that people with disabilities are a very diverse population. They're diverse not only in their disability characteristics, but also their demographic characteristics. In this case, I take statistics from ongoing work from the individual characteristics RRTC. Relative to those without disabilities, people with disabilities not surprisingly are old, have less education, and are less likely to be married.   
 Each of these characteristics could put them at risk for employment losses, particularly during economic downtowns. The differences in employment rates between those with and without disabilities are largest in the most vulnerably economic groups. For example, when you compare adults with high school educations, the employment gaps that I mentioned in the previous slide are largest for those with the most limited educations. Thus, those that are at risk in the labor market for poor potential employment outcomes are particularly at risk when they have a disability.   
 The second policy challenge I think facing our panel today is the fragmented disability system, which is depicted in this chart, which I should really cite Dave Stapleton for, because he came up with this beautiful picture. And I think it tells a very disturbing picture of how services are provided within the United States.   
 Going from top to bottom, I'll describe the four parts. At the top level you have taxpayers, who are contributing federal and state resources, which are used by federal and state agencies, such as SSA, HHS, USDA and sometimes a combination of supports from state and federal agencies, such as those for vocational rehabilitation.   
 There are multiple agencies which use these revenues to provide funding, and that funding is provided by network of both private and public service providers, who provide a variety of supports, which include cash, health, rehabilitation, housing and other supports.   
 Finally, for the person with the disability it ends with a complicated view of where to get those supports. There are multiple avenues, and when a people with disabilities needs a support they don't just go to one local SSA field office to get cash benefits or SNAP, there are multiple sources of supports that influences their decisions. As has been pointed out in other research, this limitation created service gaps, overlaps and conflicted objectives across programs, and to quantify the United States Government Accountability Office found substantial fragmentation in supports.   
 Over 21 federal agencies, about 190 programs, provide assistance to people with disabilities, including the diverse supports I just mentioned. Approximately half of these programs are dedicated specifically to serving people with disabilities. On top of that, there's a political challenge, which in addition more than 10 congressional committees had jurisdiction over 21 federal agencies providing support. I think this last point is particularly important for the agency leads as they consider how best to coordinate services for this complicated system.   
 The third challenge I see facing the panel is dealing with work disincentives, which are created in part because of this fragmented disability system that I noted on the previous slide. One of the first points, I think this is really important, is that there's limited spending on employment supports, especially relative to cash and health supports. It talks ‑‑ that tells you something about the priorities of spending.   
 Stapleton and Livermore estimate that just over 1% of federal outlays, federal and state outlays in 2008 were for employment supports for working age people with disabilities, most provided through state VR programs. That 1% is pretty telling I think of current priorities and the emphasis on employment, and could in part be contributing to these employment trends.   
 Second, as long has been established, the eligibility requirements for the major disability programs, SSI and DI, require a person show an inability to work to qualify for benefit. This focus shifts the perspective of administrators, providers and even applicants on inability to work. Even in programs like VR that emphasize work could run into outcomes. For example, in states with order of selection, which is based on severity, those on SSI and SSDI get priority, which can influence a person's decision to even apply for SSI.   
 Those are the challenges facing the panel. So let me get to what do we know about effective employment strategies. And these findings are taken from a literature review from my colleagues David Mann and Allison Tompkins of several major employment demonstrations by SSA, CMS and SAMHSA. While we covered multiple demonstrations, I'm going to focus on one recent demonstration, the youth transition demonstration, because I think each of the points on my slide are applicable to YTD. YTD included six large sites, which were implemented in multiple stages. In general, there were three sites implemented initially, and then three later sites, pilot and later implemented in a second phase.   
 The first point on my slide here is the importance of, in thinking about interventions, is piloting before going to scale, and I think that this is a repeated problem that we see. Too often there's a rush to get to scale when piloting is needed. It's sort of like thinking about drafting a first paper or first draft of a presentation or second draft, much like ‑‑ more likely to be much improved and much better.   
 The same thing applies when we're thinking about interventions. Oftentimes, we have to think through interventions and test them on the small scale before going to the large scale. This is a lesson that we learned in the implementation of Ticket to Work, and it's also, you can argue, a lesson we're learning in rollout of the healthcare website.   
 So customization and intensity also matters. This is a finding, and perhaps maybe a more obvious finding, but as Tom shows in his work summarizing the findings across the YTD sites, in general those sites with much more higher intensive services and gave youth what they wanted, which is namely the supports they wanted for a job they wanted, really mattered. As opposed to just a structural type of support.   
 This is a finding that was not only found in YTD but also in other demonstrations, like the transition‑to‑employment demonstrations as well as a variety of work demonstrations.   
 The second bullet refers to the target population, and this one is often one of the hardest to deal with, particularly in trying to think through early intervention approaches. But in general, from the interventions that we've seen tested, most of which have been tested with the late intervention perspective of dealing with program participants, rather than dealing with people at the door of application, we find that employment rates are generally higher for younger populations and the impacts are generally larger in those populations. Perhaps not surprisingly, when you compare the point estimates from the YTD demonstration to the point estimates from larger interventions, such as project network that target broad populations of SSI and SSDI beneficiaries, you see larger effects. That reflects both the customization of services, but also narrowing of target population.   
 The third point I want to make about effective employment strategies is simply one about goals. Everyone has to understand them. I think the best illustration that I can give of this is when I went to a YTD site in West Virginia that had the largest impacts of the six YTD sites. I asked some simple questions to both youth as well as the frontline workers that were providing services, and I asked them separately. I said, What was the goal of the intervention? This is actually in the research. You will get confused interpretations of the goal, but in West Virginia when we did the site visits the goal was clear. As a matter of fact, the name of the project was called Youth Works. They almost looked at me and said, It's called Youth Works, stupid, so the goal is working.   
[Laughter]  
I was surprised, in part, how consistent the answer was. I think that tells you something about the importance of not only designing early intervention supports, but also designing supports where the outcomes are clear to administrators as well as the youth with disabilities.   
 So what don't we know about effective employment strategies? This is the bad news. This is the direction that I think you need to address going forward.   
 First, there's a lack of evidence on the potential of coordinated and early intervention approaches. Under the current system, it's really hard to, as I mentioned before, identify target population to provide just in time supports that are customized to meet the person's needs and to keep them attached to the labor force system.   
 Specifically, the disability supports systems fragmentation makes it difficult to design, test and implement even modest employment interventions. For example, any intervention designed to modify supports across agencies, the sponsoring entity must first convince every agency with relevant authority to participate and coordinate and test the intervention, which can be quite difficult. My colleague Dina Livermore, in the audience, reviewed 27 federally sponsored employment programs, policies and initiatives and found most were not rigorously evaluated, due in part because of the limited planned evaluation framework.   
 Second, there is a lack of systemic tests, specifically if you think about the current set of disability supports and the test of providing supports, of cash supports to people with disabilities. There hasn't been an alternative test providing a different stream of supports or how those supports are delivered or who provides those cash benefits. Rather, there have been incremental changes to rules, but generally the overall infrastructure has remained the same. This is even true in the youth transition demonstration that I mentioned.   
 So let me summarize here the major points, and I will turn it over to the panel. First, the employment trends, and I should probably say the employment and poverty trends as well as government spending. I think the downward trends indicate a continued policy problem. I suspect that's not a surprise to many in the audience.   
 I think the real challenge is dealing with how to reverse that trend, how to deal with the diverse population with multiple at‑risk characteristics, how to deal with fragmented support systems, and how to deal with large work disincentives and lack of coordination. It will be very interesting to hear how the agency leads talk about this today.   
 The good news is that the evidence suggests some potential to address these changes, customize supports to well‑targeted populations with clear emphasis on employment are promising.   
 The bad news is, how do we go further? How do we reverse these global trends? I think that there is a challenge in terms of developing incremental policies, often implemented through a single agency, versus testing systemic changes, which are cross‑system.   
 I want to say, I want to end it at present, that actually we don't have enough information to know right now what might work systemically.   
 Later today, at 3:30 in the secretary's innovation presentation, they're going to provide examples of promising international programs, but we don't know how they might work within the US, and they actually may work much worse, might not work at all within the US, and people may fare worse.   
 So as we think about what's left here today, I think it is important for the discussion this afternoon to think about, OK, what can we do incrementally and what should we be thinking about systemically if we're really serious about changing the trends that I showed earlier in my presentation.   
 So thank you very much.   
[Applause]  
>> Henry Claypool: So we'd like to invite our federal agency panelists to come up.   
 OK. Well, thank you again, folks, for joining us today. We've got a distinguished panel. Part of it will be the reaction to today's presentation, but we also invited these representatives of the federal agencies to speak to some of their priorities. We wanted to try and narrow in on employment, but again, we may see some other issues emerge as they share with us the agency priorities.   
 So it's my privilege as a recovering fed or post whatever, federal or public service recidivist, to introduce three currently serving champions, and all friends of mine. I'm very privileged, and my pleasure to introduce to you three folks that I think we all know.   
 I will read from their bios, and I will go over them quickly, and then we will turn it over to each of them. But I will introduce them.   
 First, you will hear from Sharon Lewis. Sharon serves as principal deputy administrator for the Administration on Community Living and serves as Secretary Sebelius' senior advisor on disability policy. Previously, she served as the commissioner for the Administration on Developmental Disabilities and Intellectual Disabilities, and prior to that you may have known her with her stint on the Hill, where she served with great distinction. She's also been honored and acknowledged by groups like CCD for her contributions over the years. So we're really pleased to have Sharon in her role leading at HHS on disabilities.   
 Next, we'll hear from Charlie Lakin. Charlie ‑‑ gosh, Charlie.   
[Laughter]  
He's an oracle of wisdom, and it's great to have him over at NIDRR. As the director there, he's located in the Office of Special Education and Rehabilitation Services. Prior to coming to us, Charlie was at University of Minnesota working away on his RRTC around community living, which I think he had had for a number of years, and his contributions are, I think, widely known and often cited. So Charlie brings to us over 40 years of experience as a teacher, researcher, consultant and advocate for people with disabilities.   
 And now, to Jennifer Sheehy. We'll hear from her as the Deputy Assistant Secretary in the Office of Disability Employment Policy at the Department of Labor. But you also may know her from her years at the Department of Education, where Jennifer worked in a variety of capacities, and she served as a director of policy and planning in the Office of Special Education and Rehab Services. She was the acting director of NIDRR and acting deputy commissioner of RSA. She's been in many different roles around disability issues and served on the Presidential Task Force for Employment of People with Disabilities.   
 With that, I will turn it over to our panelists. Thanks, Sharon.

>> Sharon Lewis: Well, good afternoon, and thank you for all spending this wintry day here. Glad to see some faces in the room. Not everybody enjoying this at home in their flannel, watching on the internet.   
 I'm going to talk a little bit about HHS and move towards this focus on employment and some of the priorities that we're working on, and I think that the two things, community living and employment, are so absolutely intertwined that we cannot separate those conversations.   
 At HHS one of the things that happened when we established the Administration for Community Living is we really created a focus around these issues as it relates to people with disabilities and older populations. And in that the secretary acknowledged that the only way that we are going to be effective is if we're able to harness all of the resources of HHS, not just the small ACL within HHS, and in doing that establish the HHS Community Living Council, which is chaired by CMS and ACL.   
 You know, it's interesting when we talk about Medicaid as it relates to employment, because we have substantial Medicaid investments that go into insuring that people are able to live in their communities, but also able to work.   
 So this conversation in the context of the community living conversation is critically important. One of the elements that the Community Living Council is focused upon is both the idea of best practice as well as measurement of quality as it relates to community living and, inherently within that, employment outcomes.   
 The group has set a goal of identifying, developing, and implementing standardized measures of quality community living that can be used by HHS, states and other public and private entities to ensure the quality of and access to services and supports being provided in the community for populations in need of and/or who use home and community‑based long‑term services and supports, regardless of payer. And we are engaged actively with the National Quality Forum. The Affordable Care Act creates a terrific opportunity under the National Quality strategy to really rethink how are we going to measure the quality and the outcomes as it relates to the billions of dollars, $130 billion or so we invest through Medicaid in home and community‑based services and long‑term services and supports. That's an important element of the work we're doing.

One piece of that conversation in terms of again identifying best practices is a partnership we're engaged in with NIDRR around the establishment of an RRTC focused on community living, again so that we can understand the best in promising practices in our long‑term service and support systems and how we are best supporting individuals, both in terms of their residential and day‑to‑day home support needs, but then also in terms of their broader engagement in the community, including employment, and really trying to focus within that RRTC around community living and employment as a component of community living as well as the quality aspects of HCBS.   
 One other thing, investment that ACL specifically is making that I think, I'll tie this back around towards the end here, is around rethinking and looking at how do we start this conversation early around supporting families. What we know for youth and young adults with disabilities is that the message that they receive through all of our systems, whether we're talking about education, human services or talking through our medical systems matters in terms of understanding the expectation and whether an individual at age 18 is completing school with an expectation of going directly onto SSI and, therefore, changing their employment outcomes inherently, or are they setting different expectations early on.   
 So one of the investments that ACL is making is with six states, looking at this issue of how do we over the life course change the conversation in supporting families so that they are facilitating a life that engages and involves employment as the desired outcome, as well as interdependent living and the opportunity for folks to not graduate from 20 or 22 years of education to their parents' couch. So that's another important investment we're making.   
 We also think that workforce development is an important topic and issue, both on the provider side and obviously in healthcare system. This is an important issue that HHS is very engaged in. When we talk about really thinking about what are the strategies and metrics for assessing the capacity and effectiveness of our workforce, we see that including our direct support workers, our informal caregivers and others who then facilitate the opportunity for individuals to be fully included and to participate in employment, and so our colleagues at ASPE are developing a framework, strategy and metrics for assessing those elements.   
 ACL on the workforce element is also, through our Wrong Door Initiatives, the ADRCs, changing how we're talking about the qualifications and the opportunities for individuals who are working in those systems to work with all populations and all payers, and really moving towards a person‑centered focus, and working with folks like Michael Small to improve how we again talk to, think about and support individuals who are coming through that system.   
 So those are some of the health‑related pieces that HHS is focused on that I think all ultimately wrap around people in order to improve the employment outcomes.   
 The Affordable Care Act creates this great opportunity, right? I think one of the theories that we have to test moving forward is whether or not access to employer‑based coverage or through marketplace is going to fundamentally alter any of the employment outcomes for people with disabilities now that they're able to access health insurance and not presume to need Medicaid as the only option. So I think our ability to understand that is critically important, and that's a research need that I don't know that is being adequately addressed.   
 We have some initial data in looking at populations with mental illness that shows that the combination is important. We have to have access to both the employer sponsored coverage in terms of an adequate health basis, but then also the long‑term services and supports, and if that second part isn't there the healthcare matters less.   
 Another investment that ACL is making specifically related to employment, and I think it ties nicely into one of the things Dave talked about, is what we call the Partnership for Employment Systems change grants. These are grants that went out to eight states, that are being evaluated by LUIN to really help systems prioritize employment as the first and preferred outcome for youth and young adults with disabilities.   
 I think one of the keys to that particular project is that in order to get the grants states had to have the Department of Education, the vocational rehabilitation folks, the DD Council representing a family and consumer perspective, as well as the Medicaid system at the table in order to even access the federal funds.   
 Those grants have been doing two things. They've been working both on statewide systemic issues in terms of things like, in one state they were able to get the VR system to move from doing their assessments in sheltered workshop environments to doing all community‑based assessments, then seeing some changes in terms of the outcomes for youth, because again that expectation piece becomes critical. So that's another important project.   
 In my last minute or so here, I guess there are two other points I wanted to make. Again, Medicaid is an important payer in this, and there are great opportunities to use Medicaid resources in order to support individuals with disabilities, and we have some important findings around Medicaid buy‑in and how enrollees are able to improve their employment outcomes, but we have a lot of work left to do. And we do see improved earnings for the buy‑in beneficiaries relative to other Medicaid recipients.   
 In terms of moving forward, I think that this focus on youth has been an important part of the work. Certainly, Department of Education, Department of Labor, HHS and Social Security Administration have been working together on an initiative related to transitioning youth and beginning to try and get to some of the silos and fragmentation that we know exist across the programs, but some of it is very difficult, because a lot of it is statutory in terms of the programs.   
 I think this issue of expectations is critically important. We are trying to bring employment into our conversations when we're talking about education of very, very young children and families, because I think that if we don't we don't move the needle.   
 We very rarely talk to families about the expectations for their youth or young adult in terms of employment and post‑school outcomes. The assumptions are often Social Security and poverty and government programs, and I think that that is another piece of what we are trying to understand when we look at family support issues.   
 And then I think, the last piece that I think is really important in all of this is again moving towards some consistency around how our various systems cross‑disability are working together. We know this. We've had these conversations for years in terms of federal programs not being coordinated, living in silos, and how do we break through that.   
 I think it absolutely continues to be a challenge. I think we need to find ways for the administration and our friends on the Hill to work together, because I think many of those barriers are statutory in nature, and the challenges are difficult, but I think that we are willing partners in terms of bringing our resources together and trying to bring some change to bear on the employment questions.   
 Thank you.   
[Applause]  
>> Charlie Lakin: Henry, thank you for that nice introduction. Thank you, Dave. Where'd she go? Oh, yes. For those lovely presentations this morning and this afternoon. You did NIDRR proud. We're pleased to have you as our grantees.   
 NIDRR is the largest federal research program in the area of disability, but importantly it's just one of many, and many of our challenges come from that fact, that there are many and we don't often work together as well as we should.   
 The spirit of NIDRR really comes from the Rehabilitation Act, which authorizes it, and particularly a congressional finding that leads off that act, that says that disability is a natural part of the human experience, and that in no way diminishes people's right to live independently, to make choices, the choice of self‑determination, to really enjoy the full inclusion and integration into the economic, social, cultural, political and educational mainstream of American society.   
 NIDRR's job, really, is to use research to try and keep that promise that's been made to the people with disabilities. We do that through generating information through our research, through trying to promote the effective use of that research in changing the life experience of people with disabilities, and then trying to expand society's capacity to provide opportunities for people with disabilities. Among NIDRR's crowning achievements in those areas are the development of the concept of universal design and our continuing funding of ways to expand universal design; our historic leadership in accommodations, in computer, then web, now cloud technologies, so that people with disabilities are not only not included in the benefits of those, but actually they contribute to the well‑being of people. We also have a national network of Americans with Disabilities Act resource centers that provide assistance around the country to over 120,000 people each year who contact those centers for assistance.   
 We've got a lot going on, but we are really challenged by the scope of our mandate, which includes people with all kinds of disabilities, whether physical, psychiatric, sensory, cognitive. And there's a lot of talk today and elsewhere about disability, but in reality there are many kinds of disability and there are levels of severity in disability, and all of those have implications to people's ability to live independently and to enjoy the benefits of their labor. We're also challenged to support people as children, as working‑age adults, and as people who are aging into disability and people who are aging with disability.   
 We have a focus on interagency collaboration. NIDRR works with 20 different federal agencies right now, ranging from the Department of Transportation to the Department of Defense to the National Institutes on Health, the National Institute on Standards and Technology, SAMHSA and all sorts of organizations, including ACL which Sharon mentioned.   
 Moving forward next year, and I want to say, we are really committed to these collaborations. We invest in it. We spend NIDRR money to work with other agencies, because we believe that this is our only way to truly affect things.   
 People with disabilities have been telling us that transportation is one of their major problems in life. Well, we're entering into an accessible transportation initiative with the Department of Transportation to see if we can do something about that, to use technology to improve people's access, to ways to get where they want to go, to live the lives they want to live.   
 NIDRR is really focused too on making the best use we can of the NIDRR resources out there. So we're working hard to link the 240 grantees that NIDRR has with agencies who can use that expertise in their work.   
 Recently, we've connected our traumatic brain injury programs and our Americans with Disabilities Act programs with ACL so that they can be a resource to the aging and disability resource centers and other programs. So we're going to work on that. We think it's really important. We think it's important to connect with agencies like the Department of Justice and ACL so that we can not just mandate that people do things within states, but we can help them do them better, and to use data to improve their systems.   
 So these are our core beliefs, our core areas of function are really employment, community living and health and function of people with disabilities. And then, of course, we have these cross‑cutting responsibilities in disability statistics, in engineering and technology, knowledge translation is an area in which we are investing more and more.   
 We have a responsibility for capacity building, to develop new generations of researchers who can carry on the work that's been talked about to date. We operate from a five‑year plan. That five‑year plan has three major themes in it. We want to have a good distribution of how we spend our money; we want to be reasonably well distributed, equally distributed across the areas of employment, community living, and health; we want to be reasonably distributed across domains of disability, psychiatric, cognitive, physical, sensory; and we want to change our distribution between the projects that NIDRR directs and the projects that emerge from the field.   
 We have directed almost all of our portfolio in the past based on NIDRR's sense of what the world needs. We want to shift that. We think the solutions to people's problems more often are going to be determined by thinking out in the communities rather than within our little offices.   
 We want to increase the relevance of what we're doing. We're creating a Rehabilitation Research Advisory Council. The announcement for membership should be coming out in the next week or so. That will be made up of a majority of people with disabilities. We want people who really have a vision of what NIDRR can become to be part of that. We also have increased relevance as the way we judge the quality of our applications.   
 Then, with regard to quality, nothing is more important in the quality of our work than peer reviews. So please, please, if you're interested in the quality of what NIDRR does become a peer reviewer. OK? It's easy. Send us a note to nidrr‑mailbox@ed.gov and we will welcome you.   
 Dave talked about how we need to work more systematically in our research programs, to move from discovery, the kinds of statistics that were provided today, to developing ideas about interventions that might work, but to test them, to field test them, then to work toward interventions that are tested in well‑designed experiments, then moving to program and policy innovations. We're really committed to that.   
 We want to push our research to the area of program and policy reform, but we want to do it systematically. So we ask people to think about what stage we're at in the knowledge development that we need to get people where they want to live.   
 In recent years we've moved considerably away from medical rehab. We fund seven less centers than medical rehab now than we did three years ago. We've invested those resources into employment and, to some extent, into community living. But mostly in employment, with seven new centers ‑‑ or five new centers in employment.   
 We've invested a lot in what we call our Disability Rehabilitation Research Program, $500,000 a year for five years to come up with field‑initiated ideas about how we can improve the lives of people with disabilities. We've invested about half that in the area of employment. We really think that we need ideas from the field if we're going to move the needle on employment.   
 We're funding, also in our field initiated program, our research and engineering centers, doing more field initiation in those areas too, technology for vocational rehabilitation, information and computer technology, mobility and also physical access and transportation.   
 We are still directing some centers. We want a center on technology for cognitive impairment in employment. We want to see if we can use technology to replace the hand‑over‑hand supported employment practices that are so often dominant in supported employment settings. Can we use technology to replace that very intense kind of support that people need? We want to develop technology for independent aging.   
 Let me talk just a little bit about 2014. We're going to continue our commitment to employment. We're going to jointly fund three research and training centers with SAMHSA in the area of transition and employment. We're really committed to working with Rehabilitation Service Administration. We're going to be doing some work in return on investment. We're going to do some work on management and evaluation. We're going to re‑create, as we said in our long‑range plan, a center on employment of people with intellectual disabilities. That was one of our most notable areas, of really the area in which supported employment originated, and that center sort of fell off the table for a while. We're going to get going on that again.   
 We're expecting good work from these field‑initiated things as we've had in the past. I can't go over all of them, but they're really promising innovations. At Indiana University they're bringing vocational rehabilitation specialists from the VR agency, people from employment providers into the schools to start working with kids while they're still in the schools.   
 We had a field‑initiated program a while back working with kids with autism, that took kids, put them in Project SEARCH in a one‑year internship, with intense training both for the individuals and the support providers, in hospitals in Virginia.   
 The results of that was that 87% of the kids who went through that program were employed three months after their graduation. The control group, who just went to the ready special ed programs in the same towns these other kids came from were employed at a rate of 6%. 87% vs. 6%. We're going to continue to follow up that first cohort, but expand this to some new hospitals to see whether we can get the same results.   
 As we look to the future, we want to do more sound research, expanding what we know, but we really want to struggle with this issue of narrowing the gap between what we know and what we do. We want to think about how to get that 87% more generalized across our society.   
 We need to invest in making what's possible a more typical experience for people with disabilities. We want to focus on scaling up programs from interventions to common practice. We want to focus on building an evidence‑based for interventions. You know, it's generally important to have evidence‑based practice, but increasingly important as we move into a more managed care mentality in which people are going to ask more and more, "What's the evidence that investing in this program or policy really will yield rewards?"   
 We want to integrate what's known into the continuing education or vocational rehabilitation and other service providers. It doesn't matter if we know it, but the people who provide the hands‑on support don't know it. So we have a big challenge there, because these people work in more and more dispersed sites at odder and odder hours, and we have real difficulty in reaching them with state‑of‑the‑art practices.   
 We want to increase our collaboration, cooperation and consolidation of activities among agencies. There's no agency in this government that has enough resource to do all that we need to do. So we need to do it together, and as I said, NIDRR is really ready to invest its resources in doing that.   
 We really need to use knowledge translation and dissemination to raise people's expectations. Dave mentioned that. We've got to raise the demand side for good practice, and the only way we can do that is to convince people that they can expect more out of life than they have been expecting.   
 We need to use information to improve the recruitments, support and recognition of employers. Bill Erickson is here from our Cornell center on employers. We are really committed to the notion that we've got to improve the number of employers who are willing to try, because we think if they try they'll experience what Walgreens and others have tried.   
 Then we really need to work together to reduce disincentives in our policies. You know, even in that successful program that I mentioned in Virginia, only ‑‑ the average number of hours that graduates worked was 18. If you look at the national core indicators data from several states the average number of hours that people with developmental disabilities, who are working in competitive employment, worked per week is about 15.   
 Why is that? Well, you all know the answer. We talked a little bit about it today. People run the risk of losing things they can't afford to lose. So somehow we've got to work together to separate earnings and assets from benefits. If you make a lot of money, you should help pay for your benefits. But you should not be risking the loss of those benefits if your income or job is lost. You know, the only group in America that can make too much money is people with disabilities. We really need to work together to change that.   
 Well, I could go on. You know, we're amassing so much information and accomplishing so little with it. I really believe there's a lot we can do, but we can't do it unless we work together.   
[Applause]  
>> Jennifer Sheehy: Thank you. Oh, it is on. Not if I drop it. Thank you very much. I'm Jennifer Sheehy with the Office of Disability Employment Policy, and it's really a privilege to be here with this group of distinguished people, and Henry, who is also distinguished, of course, in his own right.   
 Working as a federal employee isn't nearly as glamorous or perk filled as I guess it used to be, but one of the real joys is getting to work with my colleagues here in other agencies, and I feel like we are really doing a lot to make a difference together. I think that's something that we will continue to do, and as Charlie said really invest with money to show that this is the trend of the future and the only way that things are going to work.   
 So the Office of Disability Employment Policy, our mission is to improve the number and quality of jobs for people with disabilities. Obviously, that is a tough, tough goal. Given the complexity of employment, the variety of disability, it sometimes makes me think of a quote by Mitch Hedberg, he's an author and comedian who said, "I'm sick of following my dreams. I just want to find out where they're going and then hook up with them later."   
[Laughter]  
I sometimes feel like a person with a disability has dreams, and of course we need to promote high expectations, particularly with young people, but it's an intimidating process trying to get there. So we really do all need to work together to make it simpler, to streamline it and to really make it a reality for folks.   
 In the Office of Disability Employment Policy we have four priority areas. The first is initiatives that promote training, education, transition and employment opportunities.   
 The second is looking at employment supports and accommodations.   
 Third is increasing expectations and improving perceptions, really getting rid of those myths that have been persistent that contribute to attitudinal barriers.   
 And finally, data and statistics, increasing the use and availability of data, and we've enjoyed our partnerships with the Bureau of Labor Statistics and the US Census Bureau to help with new data points. You heard today we have over a billion new data points. But also look at increasing the capacity for analysis. Because, it's super important, we have a lot of aggregate data, and we can look at trends across the "disability community ,"but in order to really test and validate good practices for employment, we really need to dig down, and I'll talk about that a little bit later.   
 So within our priority areas in 2014 we have a number of initiatives that we're working on. Every one of them is in partnership with other agencies and partners, sometimes employers, sometimes nonprofits, sometimes researchers, and state and local governments as well.   
 For instance, the Disability Employment Initiative, this is an initiative that looks at using the one‑stop system, which is now the American Job Centers, to make sure they have the capacity to serve people with disabilities, so that when you come to an American Job Center that they can address the needs and help serve them with their own programs, rather than saying, Oh, it's a person with a disability, I think we need to call that VR counselor over and just let them handle this particular case.   
 That's been an initiative that's gone on for a few years now, and it's been heavily funded by Congress and we're very grateful for that funding, but we have a ways to go and we hope that we will be able to continue this funding.   
 The second is the Federal Partners in Transition, and that is again with HHS, SSA and ‑‑ I'm sorry, and Ed, Department of Education, and we have been tasked by GAO and by Congress with working together to put together a strategic plan vision for 2020, really streamlining services and programs, looking at policy barriers and recommendations, and moving forward too, so that early intervention with youth with disabilities makes a difference and can send them into a career of their choice, rather than to the SSI or eventually SSDI roles.   
 That's a partnership that is also part of our National Youth Transition TA Center, and we work with the Institute for Educational Leadership, the grantee there, to develop soft skills curriculum, professional development, look at ways of delivering information and using the latest technology and popular social media to youth. So it's where they are and it's useful to them just at the time that they need it.   
 Another is our Employment First State Mentoring Leadership Program. This is again in combination with other agency partners, but it's really pushing the priority of integrated competitive employment for people with significant disabilities as a first option.   
 You've heard that ‑‑ it used to be a common theme, which is a good thing. You've heard that from other colleagues today, that this is something that we want states in particular to understand how to do, how to implement.   
 We talked a little bit earlier, and thank you to David for setting kind of an agenda and framework, about what we can do with less funding. We have a trend that probably won't be going away for a while. There are really three things. One is to look at the resources that we have that are not necessarily disability specific and make sure that they have the capacity to serve people with disabilities, and that includes work with the American Job Centers.   
 Two is really focusing early and making sure that youth with disabilities have what they need and know what their options are and get the right supports so that they are on a much better trajectory.   
 And third is making sure that people know what they can do now. We recently, as part of our Federal Partners in Transition work, held a national online dialogue to find out what the regulatory and legislative barriers were for young people with disabilities. So many of the barriers that were mentioned were things that were perceived barriers, where you can really coordinate funding, combine funding, when you work across agencies. It just highlights the fact that we need to get the right information out, demystify Social Security options and IDEA policy and vocational rehabilitation policy.   
 So those are three things we can do now with limited funding environments that will help really improve the state for people with disabilities.   
 A few other of our 14 efforts, we have a fantastic Campaign for Disability Employment, and you can go to ODEP's website, dol.gov/odep, and look up all of these initiatives.   
 We have several public service advertisements that have been extremely successful. In fact, the one currently running, because it's focused on youth and expectations and what adults can do to really encourage and help young people, and it is in the top 2% of Nielsen ratings of all public service ads right now. It's had more than $60 million in in‑kind media time. So that's remarkable, and it does get the word out.   
 We sponsor the National Disability Employment Awareness Month activities and work on the theme and develop posters that can be downloaded by communities and schools and entities across the country.   
 So we have a lot of public outreach campaigns and materials. We are also working on return‑to‑work, working with disability insurers and nonprofit partners and Social Security and other agencies to contribute to that discussion and kind of latching on to the tail of the SSDI reform discussions to make sure that the supports are there for someone early enough, so that if they are experiencing an exacerbation in a disability or condition that they have what they need, so it doesn't get to the point where they have to leave work, or if they do have to leave work that they can come back quickly and maintain their relationship with their employer and with the workplace.   
 We have really exciting work going on in what we used to call the business case, which was how to quantify the benefits from the employer perspective for hiring people with disabilities.   
 Well, I think everybody here, we're all ‑‑ we all work for employers too, and hiring managers, and I think we all know that when you're hiring someone you're not thinking "What can I do to help benefit this particular community?," you're thinking, "Is this the right person for the job?"   
 So this is what we need to know: We need to know more about how employers make their decisions, how employers institute policies that are diversity policies, HR policies, procurement policies, marketing policies, so that people with disabilities are considered because of their talents and not for other reasons. That's what we're hearing from employers. We know that employers do have attitudes and preconceived notions, and we want to make sure that they know that there are case studies, best practices that people with disabilities can do that particular job that they are hiring.   
 We need to do a better job promoting the value and the asset of people with disabilities, and particularly with employers we want to stop talking about the negative employment statistics for people with disabilities. It's OK for all of us internally here to talk about it. We need to know what our mandate is and how to measure our progress. But when employers hear things like 70% of people with disabilities aren't working, 80% are out of the labor force and 13% unemployment, they think, Well, there's something wrong with those people, so I'm not going to hire them. Or, B, Everyone else is not hiring them, so I'm not either, certainly not going to get in trouble for it.   
 So those are some things we're learning. It's fascinating. We're continuing to invest in some of that research.   
 A couple of things to think about going forward, some questions that are coming up that from our initiatives and trends we're seeing. Again, because of the variety of condition, functionality, complexity of employment issues, we and our new billion data statistics, we really need to dig down further and try to put smaller pictures together, so that we can identify the best practices for employment for particular populations, geographic areas, industries, ages. There are so many ways we can cut it.   
 We definitely want to look at what we're learning in other research disciplines. We have started putting together what we're finding in behavioral economics, organizational behavior and change management, social psychology and marketing, particularly to address the employer, the demand side of the equation.   
 What do we know about social enterprise projects or social marketing campaigns? How can we capitalize on the interests now that Section 503 has set a 7% aspirational goal for federal contractors?   
 We get calls every single day asking where we can ‑‑ where employers can find people with disabilities and how to rate disability consultants. Do we have any recommendations on disability consultants?   
 Well, we can't endorse disability consultants, but it certainly is a great business opportunity if someone wanted to set up an Angie's List or Yelp or some kind of website so that they can register, they can be recognized as an expert and then get ratings. Employers would love that. We're finding that out.   
 We have internal to DOL a huge emphasis on measuring performance. It's very hard for a policy office to measure impact, and we measure it through adoption and implementation of our policies and practices. That is so hard.   
 Often, we will hear something on NPR driving in and said, They're using our soft skills curriculum in Indiana. Write it down quickly! Get it to our Deputy Secretary.   
 It's really hard to capture that, and sometimes you can't capture it for 10 years. It takes a long time sometimes for policies to sink in and, say, convince people it's something to try, then try it and find out it's effective.   
 So going forward, we're really looking for good ways to measure our policy impact and performance. We know that foundations, major foundations, have typically not funded disability, and that they say disability isn't part of their mandate. But we also know that so many of the populations or issues that they do care about have to do with disabilities or are disability issues. So we need to do a better job showing the correlation and can use data to do this of issues that are already in the media or foundations are funding, like poverty or childhood obesity, prison overcrowding, school‑to‑prison pipeline or disconnect to youth. These are all major issues that have a lot to do with disability.   
 And then we have to look at, and I think we have a great opportunity and a lot of people, the right people in this room right now, to do analysis of big data. HHS has done a great job putting their administrative data online, making it very public and holding things like hackathons to develop apps that then serve the public.   
 They put together this hackathon. It was a two‑day intense developer conference where they came in, they were shown what data was available to them, and then they said, OK, how do we take healthcare administrative data, Medicaid data, Medicare data and combine it with GPS data or some other publicly available data, and put together services that they get paid to use? So that these are new businesses. Entrepreneurs come into these hackathons. What can we do with our big data, what can we do with the disability big data to encourage entrepreneurs to think of great services that can benefit the folks that we work with on a daily basis and serve?

And then, of course, going forward how do we work better? We know that working across silos or taking away those silo walls is very difficult, and we know that often it is not the policy that's the barrier or the funding issues that are the barrier; we know that it's actually the people‑to‑people connections that can really impose the hardest barriers to crack. So that's something that we want to focus on. We have great examples in states and local communities and in the federal government of where it is working. We just need to get that out there.   
 Thank you very much, and I think we would all like to entertain your questions.   
[Applause]  
>> Henry Claypool: So thank you. I think we have a few minutes for a couple of questions. Thanks again to the panel. Maybe I'll build on Jennifer's last comment and throw out a question, bringing back Dave's kind of trends.   
 I think education is a huge trend that not only people with disabilities but people as a broader society are struggling with; the correlation between educational achievement and employment outcomes are pretty clear. Here we have a group of folks that represent federal governments, and perhaps the programs that they are responsible for are somewhere on Dave Stapleton's chart of fragmented programs.   
 Embedded in my question is the hope that through an interagency effort you can not only address some of that fragmentation, but then develop some capacity to tackle the work disincentives that were raised.   
 I would ask the panel if there are any quick comments on interagency efforts that are under way, that you didn't mention in your remarks, that you think might help us address some of the fragmentation that's been raised. Or even in your remarks.

>> Sharon Lewis: You're Department of Ed. You get to tell them about it.

>> Charlie Lakin: Yeah. Well, there are efforts, some of which we're compelled to participate in. One of those was the Promise Initiative in which I think now six grants covering about 12 states have engaged in a major intervention for youth who are on supplemental security income, to provide supports to those individuals and to their families to move them into sort of a nonbenefit status as they reach adulthood. That's just getting started. The applications require people to really dig into what we know about transition services, to include things like providing people with work experience as they're in school, to provide families with training both about benefits but also about supporting their children to move into work settings.   
 So, you know, we're hopeful that ‑‑ Dave mentioned the youth transition demonstration that was the predecessor of this effort. We're hopeful in this second iteration that more of what we know will be integrated into those programs from the beginning. But it's just kicking off. It will be years before we know how it works out, but it is an effort not only to integrate what we know but to integrate into the interventions for these youth all of the agencies that have a stake in their futures, from Health and Human Services, Education, Social Security, Vocational Rehabilitation and so forth. So we can hope but we will have to wait, I guess.   
>> Hi. I'm the author of the chart that Henry just mentioned. I first want to say the disclaimer. It's not accurate. It's much, much simpler in reality.   
[Laughter]  
But following up on your mention of Promise. I want to commend you for all of the work that you guys have done, the cross‑agency work. It's been a lot more than we saw in the previous administration. I just hope there's some momentum to keep that going. For a few years, at least. Following up on Promise, I wonder if there are other ‑‑ a lot of people were interested and learned about Promise late in the game, including me. Maybe I'm clueless. I wonder if there are other things coming down the pike that you can share with us.

>> Charlie Lakin: Well, nothing with that price tag, I can assure you.   
[Laughter]  
But there is ‑‑ there are efforts really around transition, to see whether agencies working together can make a difference in this.   
 There's sort of a sense emerging, I think, that we don't ‑‑ we're not going to probably do as well at solving this employment program working with people who are already sort of intractably mired in our disability, what, quagmire? But that by taking people who are about to enter it and changing the trajectory of their lives, that we might have more success, that we might be able to get people to enter adulthood with a different set of expectations and a different set of probabilities than those of people who are older. So a lot of work in trying to get us to work together. I think some of it's successful. I think some of it's challenged by the same challenges that are evident in the contemporary system, that the benefits programs create circumstances in which people, if not feeling disincentives for work, feel real fear about what taking that big step could mean to them, if that big step kind of leads them to fall off a curb.   
 So everyone's committed to working together. I think everyone's committed to solving these, or at least identifying the solutions to these challenges, but of course solving them is something that is really not within our power in many cases.

>> Sharon Lewis: Echoing Charlie's comment in terms of something that has that kind of investment, I don't see anything on the horizon. I think one other collaborative that has been taking place across all of our agencies, as well as the Department of Justice and EEOC, has been a group looking at the distinctions between competitive and integrated employment opportunities relative to segregated, enclave, sheltered workshop approaches, and looking at that through an Olmstead lens. I think that has created some very, very good conversations at HHS. As a reminder to folks who don't follow Medicaid policy quite as closely, we do anticipate the new 1915 settings reg, which really defines where Medicaid resources can be expended in terms of home and community‑based services.   
 If you go back and look at that, notice the proposed rulemaking, it was clear that we're talking about all settings, not just residential settings. As we think about what it means to expend those resources, and I think we're hopeful that that regulatory change may have some substantial effect in the states in terms of where those Medicaid dollars are being expended as it relates to employment, kind of building on the information bulletin that Medicaid put out in September of 2011, focusing on where should Medicaid dollars be expended as it relates to prevocational services and employment services.   
 So I think that's another thing on the horizon. Department of Justice has been focused on this in terms of looking at it through an Olmstead lens, and it will be interesting to see where that goes as it relates to understanding the opportunities for individuals to be supported in working and employment.   
>> I've got a couple different questions. One is, where is the Department of Education? I'm missing that piece of the puzzle here. When we're talking transition, I don't see them sitting at the table. You talked about Project SEARCH. I'm well aware of the program down in Richmond at St. Mary's. Then you talked about transition from the same school districts or employment rate at a much lower rate. So where are schools in this conversation? Are they collaborating with you?   
 The other thing I wanted to talk to, you said Department of Justice, and competitive employment and so forth. Any word on, and I don't know where this is in the legal system, about competitive salaries and minimum wage salaries for all people, and not ‑‑ there's the American Federation of the Blind that had a lawsuit out with regards to that.

>> Sharon Lewis: I'll take the end of your question first, then pass it back to Charlie and let him defend the Department of Education.   
[Laughter]  
Good luck.   
 So in terms of the Department of Justice and the issue of competitive wages, that's part of the conversation of this competitive employment workgroup, and working with the Department of Labor. I think one of the challenges is that the Fair Labor Standards Act allows to set minimum wage for people with disabilities, and I think that there are things that wage and hour can do to better enforce, and the attention paid to this issue has created opportunity in terms of understanding who these entities are that have subminimum wage certificates and what the effect is in terms of employment.   
 Department of Justice, however, in terms of there being a legal issue, this is right now a statutory issue in terms of whether Fair Labor Standards Act allows, and I think that Department of Justice, if you look what happened in Rhode Island, is focused on how do we ensure that entities that are utilizing those certificates are doing it consistent with the wage and hour requirements, and then again looking at it through this Olmstead lens around how are we making sure that folks who are interested in participating in integrated settings are being supported to do so.   
 I think that's really the hook at this point. As another colleague has said to me, this issue of subminimum wage is a difficult issue, but I think that a far more interesting issue is how are we going to ensure that we're supporting folks to access competitive integrated employment and accessing a meaningful day?   
 To Charlie's point around folks with the most significant disabilities, if an average workweek is 10‑15 hours a week and an individual needs support for the rest of the hours, what are they doing? What are their opportunities for other things that create meaningful day? And how does this fit within the realm of the full family picture. For the IDDD population we know 60% of folks are living with their families, and frequently the barrier as it relates to sheltered workshops is less around the opportunity to do other things, but how do we manage transportation, meaningful day and making sure that mom and dad, who also need to get up and go to work in the morning, have the supports they need so that all of those pieces fit together. I think it's a bigger conversation than one that I think we're happy that CMS and HHS are able to engage it, because I don't think it's just about subminimum wage.   
 One thing on the Department of Education piece: I'm not going to speak on behalf of the US Department of Education, but I can tell you that based on the eight projects we have out in the states where we're required, the Departments of Education, to participate in these grants, and they're grants that range between $300,000 and $500,000 a year for five years to states, not insignificant grants, in bringing together all of those state partners, absolutely across the board in all eight states the biggest challenge that has been reported has been about the Departments of Education, who frequently see their role as kind of a handoff in terms of students, as opposed to collaborative, cooperative engagement around transition and ensuring that we have better outcomes.   
 So I think that it continues to be a challenge both at the federal and state level.

>> Charlie Lakin: Well, first, I'm not really in a position to speak for the Department of Education. Our institute is in the Department of Education largely by accident. We are not ‑‑   
[Laughter]  
‑‑ unhappy with that placement, but we don't have ‑‑ probably education is the one area related to disability that we do nothing in.   
 I would say there is great interest and commitment to moving special education from a compliance‑based approach to one that looks at the outcomes for people. Transition is a big part of the outcomes that people would like to receive, to see achieved by schools.   
 I think anyone in a formula grant program would tell you that change is terribly, terribly hard, because really you have a spigot that you can turn on or off. Turning it off is virtually impossible, so the funds flow. Your asset is really your ability to convince people to change their behavior. So I know the department's had major conferences on transition. It's issued letters, guidance to states on transition. It wants people to leave school into a meaningful work and independent living, but it's a long chain from the Department of Education to the local school, and I can only promise you that people are committed to that. I'm hopeful that they, working with others, other agencies, will achieve a lot more in the future.

>> Jennifer Sheehy: And I also want to add that with the federal partners and the transition work, the Department of Education, the Assistant Secretary of Special Education, Rehabilitative Services, is the co‑chair with our assistant secretary, and they've had active participation from NIDRR and from the Office of Special Education Programs and the Rehabilitation Services Administration. I see Leslie Kaplan here, and she's been very active. And Charise Hunter, who works with ODEP, has been extremely helpful and active on that. Jamie Kendall and others. Bob Williams, who is in the back, trying to hide.   
[Laughter]  
Hopefully I'm not missing others that snuck in. But we do have great commitment from the Department of Education there too. And the Wage and Hour Division that administers the Fair Labor Standards Act in the Department of Labor has started a workgroup with the Department of Education Office of Civil Rights and Special Education Programs to look at how they can get better information to state education agencies on the proper, appropriate use of 14(c) waivers for young people as a short‑term, temporary training opportunity, and only that. Thank you.   
>> First, one thing I want to say is thanks to everybody for this. Every year is sort of, I guess, a highlight for folks in the disability community that do advocacy. I know there's a lot of work that goes into it. So thanks to everybody on the panels and in New Hampshire and everyone that helps get this out, that helps us out there in getting the message out, to do our jobs and really help sort of add to what we do.   
 As someone who's been blind since birth, thinks back fondly to navigating the VR system when I was a kid, I'm excited to hear a lot of the stuff still being talked about and moving forward with the youth. As someone, though, who represents the blindness community, who has been ‑‑ we've been working or managing the huge rise of the baby‑boomers and onset of later‑in‑life disabilities by generation, a wide range of varying illnesses or eye disorders that create blindness later in life, I wonder if you could speak for a few minutes on that population, because I know there's been a lot of talk about youth today. But what about those in their 40s, 50s having to leave their job dealing with the misconceptions of their hiring manager trying to come back to work, or being out of work for a year or two while they go through the rehabilitation system? What is the landscape right now, and what are some of the priorities moving forward for that population who still finds themselves having to go back to work?  
>> You left them speechless.   
[Laughter]  
>> Jennifer Sheehy: Well, as all of us over 50 know you're SOL at that point.   
[Laughter]  
No, just kidding.

So we're trying to take advantage of the demographic trend, but particularly working with employers, because as they realize, people realize that they are having function issues, and they don't think of themselves as people with disabilities, they just think they can't hear as well, see as well, move as well, think as well, and they're finding that the same tools that they need to continue to do their jobs are the same accommodations or tools that people with disabilities need when they enter their jobs.   
 So we're primarily working to make sure that employers realize that there are supports to keep the employees on the job that they've invested in throughout the years, and that in making the connection to their valued workforce and to a new potential untapped workforce of people with disabilities. Adults with disabilities, we talked a lot about transition, but most of the programs still focus on a slightly older population, and we are still working to make sure that those programs are running as smoothly as they can and are as effective and efficient as they can be.

>> Charlie Lakin: I'm sort of embarrassed to say this: Alls I know is that we fund some centers on visual impairment and employment. Most of our work is done in the area of apps, or the most frequent projects are apps that are designed for people with visual impairment. We just had a project with Treasury to develop an app for Android phones that could read currency and give people a verbal output on the denomination of the currency. It's sort of pathetic that we as a nation have to do that, since if we only made our currency of different size we'd solve the problem.   
 For the most part, I just have to say I hope our centers are doing well. I wish I could articulate something more definitive. We do work well with the AFB and take a lot of guidance from them about what work we should be funding. I have to plead an unfortunate level of ignorance about our activities.   
>> I plead lots of ignorance, but I'll ask my question anyway. I was glad to hear someone bring up the fact that education was missing from the panel, because that's one of the first things I thought about. Honestly, I've been out of the special education transition worlds for a long time, but something Sharon said really struck a chord, and I'm wondering if there has been any thought to looking at potential demonstration grants that focus on expectations and self‑determination, and really bringing it ‑‑ I'm an old middle school and high school special education teacher. Waiting till high school often, if we're talking about transitioning youth, is too late. If there could be thought to a longitudinal study that looks at starting in middle school, really looking at helping not only youth but parents and the community truly have higher expectations, I think there's so much ‑‑ I don't know that I say research‑based information, but there's so much information out there regarding if you hold people to higher levels of accountability and expectations, they will meet you at those levels. So often, I think, for good, better and indifferent reasons that the level to which we're holding youth and youth with disabilities is not the level to which they truly can perform. I don't know, just that whole conversation about expectations I think really needs more money behind it.

>> Sharon Lewis: Well, I would agree with you. I think ACL gets to plead our own kind of set of poverty issues as a small agency that doesn't have ‑‑ we don't have substantial research dollars available. We do, as I mentioned, have a project that is a community of practice across six states that are looking at this issue of supporting families through the life course, and I know that one aspect of what they're talking about looking at is how do we have these conversations actually way earlier than middle school, all the way to early intervention, early childhood special education, and begin to develop higher expectations, both within the families but also with the educators. So I think that there are some opportunities that we'll see developing through that.   
 I also know that through the AIDDD youth transition employment projects that are going on in the states a couple of the states are looking at how do we reach down even further, what are some of the conversations that need to be taking place in terms of, in particular, through the educators, because they're often the best point of contact around development of transition goals that start much, much earlier.   
 I think one of the challenges with IEPs is that they're often a one‑year event, right? We go in, we do an IEP, talk about what's going to happen this year, and we don't cascade it in the way that we think about other ladders in terms of what's the IEP for a 4‑year‑old look like that is going to result in an employment outcome at age 21? We look at what's an IEP based on the deficits we see this student exhibiting at age 4 and don't connect those dots.   
 So I think that, to Charlie's point around where the department has gone with the improvement around IDEA reporting or in‑progress IDEA reporting, around moving from this idea of compliance towards outcomes of, some of those implementation ideas have to play out in order to achieve those outcomes.

>> Henry Claypool: I'd like to take a moderator's prerogative to just opine on the question, because I think without addressing the really basic misalignment of the economic incentives, particularly for students that need ongoing services and supports, it's particularly challenging to think about what you can do to change that. Because, young people will know that the only place they can find the services and supports they need when they achieve some level of maturation or emancipation from their family, living independently, will be through a poverty program like Medicaid, and we really have to look hard at how we can find new ways to extend those services and supports, not just Medicaid funding, but in an ongoing fashion to support a population that needs some legitimate services and supports to achieve a greater level of economic self‑sufficiency, which we desperately need in this country. So the federal agencies can't do it all. It's up to some advocates too, to really take on some of the challenges that we know exist.

I just wanted to thank our panel and the audience for asking such good questions, and hopefully ‑‑

>> Colin Schwartz: Hold on.

>> Henry Claypool: Is there a Bob Williams question?

>> Colin Schwartz: There is.

>> Henry Claypool: We always have room for that.   
>> I agree with you that we need to do more in developing a range of services and supports for folks with levels of significant disability to lead meaningful lives, beyond employment. It's sad though there is great suffering, why many folks work up to 15 hours a week, many of which have a business model and incentives of providers and to change that.

>> Sharon Lewis: I think you're right, and I think there are multiple pieces of this conversation that fundamentally have to change in terms of Medicaid, Social Security, you know, what we count on from the Department of Education and where are those supports that Henry mentioned, so that folks can get to a week that is more than 15 hours. I think that's a huge piece of it, and the elephant that's always in the room is where's my tipping point in terms of loss of benefits? I think that's a fundamental problem that we have that we've all been grappling with for ‑‑ you've been grappling with it many, many years, Bob, in terms of how do we get there.   
 I don't know that we have any easy solutions, but I think that the most important aspiration that we all need to be looking towards is how do we fundamentally change this conversation so we are not dependent upon poverty programs and the assumption of poverty programs for all people with, disabilities at the point that they turn 18 or 21 or whatever that point is, in order to achieve a reasonable life. And when do we fundamentally shift the conversation to how do we get to a middle class life, so that we have more people whose worlds look like yours and Henry's and Jennifer's, without a high level of dependency on the federal programs?

>> Henry Claypool: Thanks again.   
[Applause]  
>> Debra Brucker: Thank you again for coming out for the morning and/or afternoon today. Special thanks to NIDRR for funding the employment policy RRTC as well as the StatsRRTC. I want to thank our partners in both of those RRTCs, as well as all of our speakers today.

I hope you have safe travels home. Thanks.   
[Applause]  
[Ended at 3:00 p.m.]