2014

Annual Disability Statistics Compendium

December 3, 2014

>> Debra Brucker: Good morning, everybody. We're going to get started, if people can please take their seats.

Good morning. And welcome to the 2014 annual compendium of disability statistics. We'll spend this morning reviewing current data and statistics about disability in the US as well as learning more about new data collection and dissemination efforts.

My name is Debra Brucker and I'm a researcher at the University of New Hampshire. I work at Institute on Disability there. I work closely with Andrew Houtenville, who is not able to attend today, so I will be presenting some information on his behalf.

On behalf of our whole UNH team, I'd like to thank of the National Institute on Disability and Rehabilitation Research for sponsoring this annual event.

I have some housekeeping duties to attend to, just reminding folks that restrooms are located out the door to my right. When we do have a question and answer period, we have two standing mics, as well as someone that will be able to bring a mic to people if they have any questions. For folks participating online, you're welcome to put questions in the live chat feature that you see on the event page.

Lastly, for people who may be trying to access the internet from this room without windows, the user name is intern, all capitals, and then lowercase net. So two N's. The password is SP2009TWC. We have this written on some of the tables over by the food, if you forget that and need to connect later.

I'd like to start by thanking people who made this day possible. I'd like to thank the entire UNH team for help in coordinating this event. I'd also like to thank all of our partners in the disability statistics and demographics Rehabilitation Research and Training Center, as each has played a role in helping to improve the collection, dissemination and utilization of disability statistics to better inform policy and practice.

Our partners include Mathematica Policy Research, Kessler Foundation, the Center on Disability at the Public Health Institute, Infouse, American Association of People with Disabilities and the council of state administrators of vocational rehabilitation.

In addition, and in advance, I'd like to thank each of our distinguished speakers today.

Lastly, as we anticipate over 250 online and in-person attendees today, which I believe is our largest audience yet, I'd like to thank you all for your interest. I also encourage you if you are savvy with social media, which I am not but I encourage you to tweet about our event today using hash tag compendium 2014, and #disability stats.

I would like to dedicate our event today to the memory of Terry Mcminman who passed away in 2014. He was an integral part of our event for the last many years, providing data from the Bureau of Labor Statistics. I would like to share brief remarks prepared by Steve Haugen, who worked closely with Terry at the bureau of of labor statistics.

Terry McMiniman worked as a commissioner for the bureau for 15 years. He was passionia the about his work on collecting high quality data on with a disability. He was deeply committed to making sure that data on persons with a disability were broadly available to the public and worked tirelessly to make sure these were published and accessible. He worked through the many issues associated with collecting these data, and adding the estimates to the widely watched monthly employment situation news release ensuring unemployment rates for persons with a disability were published alongside rates for other subpopulations, including race and ethnicity. He also led a team to produce an annual BLS news release devoted to the labor force characteristics of persons with a disabilities, and helped document the addition of the disability related questions to the current population survey and a monthly labor review article published earlier this year.

Terry also helped spearhead work to design survey questions for a special current population survey disability-related supplement, which was sponsored by the Office of Disability Employment Policy and administered in May 2012. The goal of the supplement was to gather additional information on the labor market issues that affect persons with a disability, such as specific barriers to employment.

The supplement also collected a range of related data germane to the labor market situation of persons with a disability, including information on their recent work experience and the types of career and financial assistance used. The data from this supplement work highlighted in the special news release issued by the BLS in April 2013. Terry often was called on to represent BLS in explaining our data to the disability community, something he had done for this group in the past. Terry was the bureau's expert when it came to our statistics on the job market situation of persons with a disability and probably one of only a handful of such experts in the entire federal statistical community.

It will take some time to rebuild the knowledge base that Terry amassed in the subject area, but Terry's legacy of professionalism and dedication to this specific subject area will not be forgotten.

I'd like to turn now to discussing the annual compendium and welcome you to our briefing of our sixth annual compendium event. The purpose of my presentation is to describe the purpose of the compendium, highlight some of the patterns and trends and the information that is included in the compendium, and mention how to access the compendium and technical assistance.

Hopefully, on your way in, somebody tried to give you one of the compendium to take with you or more. I encourage you to take them. Our 2014 version.

The compendium is designed to provide the disability community with a comprehensive set of statistics that are readily accessible, up to date, cover a variety of topics and sources, use population survey and administrative statistics. They're really a guide to existing sources of data and statistics.

It's modeled after the statistical abstracts of the US. The idea of the compendium is that people can readily access data they can use for program planning, policy making, advocacy work, grant applications, etc., and have all of that data in one place.

The compendium is designed as a comprehensive set of tables with descriptive summary pages, based on existing published statistics. It includes references to the original sources, with links to where you can access that information on the web. You can also access technical assistance by a toll-free number and/or e-mail.

We have a particular focus on state-level statistics and national trends.

The topics covered in the compendium include population size and prevalence, employment, wages and salary, poverty, veterans, health insurance coverage, health behaviors and other health statistics, information about supplemental security income, Social Security disability insurance, special education, vocational rehabilitation, and federal government spending.

We have a few cautions that we'd like to remind people, that the compendium contains statistics from different data sources, which have different methods to identify people with disabilities. So we include a glossary in the back of the compendium that explains these definitions. As an example, the definitions of employment and unemployment are constructed in very specific ways and more information about this is provided in the glossary. Again, if people have more specific questions, they're welcome to contact us by phone or e-mail for assistance.

I want to show you some of the data that is included in the compendium. We have information about population size. This slide shows civilians living in the community. Estimating in 2013 that there are around 40 million people with disabilities living in the community, based on data from the American Community Survey. So this provides a national picture. We also have this information available by state in the compendium.

We also have some information on trends in the compendium. So this slide shows civilians living in the community with and without disabilities, with 2008 to 2013. The percent of people with disabilities as a percentage of the US civilian population has crept up from 12.1% to 12.7% over that time period.

The compendium also contains information about persons with disability, different disability types. So this slide shows millions of people, data from the American Community Survey suggesting that there are about 20.7 million working age persons with disabilities in the US. And approximately half of those 20 million people have an ambulatory disability.

We have information related to employment that's included in the compendium. This slide shows differences in employment rates by type of disability as collected by the American Community Survey, showing that persons without a disability had 74% were employed in 2013, persons with a hearing limitation, 50% were employed in 2013, that was the highest employment rate for persons with disabilities. The lowest rates were for persons who reported self-care and independent living limitations, 15.2% and 15.3%.

One thing we like to look at or examine is the gap, the difference between the employment rates for persons without disabilities and persons with disabilities. This slide shows in 2008 that the gap was 38.6 points and in 2013 the gap was 40.3 points, which was actually a drop from last year, where the gap was a bit larger at 40.9 points.

We've had internal discussions about this. Some, Andrew Houtenville in particular, was happy to see that the gap was decreasing a little bit from 40.9 to 40.3. But I did remind him that still way too large, so still 40 points, percentage points.

We also had monthly trend data that's included in the compendium, and this slide just shows differences in employment. It actually needs to be switched. Labor force participation, the top line should be people without disabilities. The bottom line is people with disabilities, from 2008-2014.

The gap in labor force participation by month. And how that has grown over time, over the last six years, seven years.

This is an example showing the monthly number of SSDI applications as an example of some of the other information contained in the compendium. You can see how this fluctuates over time. This afternoon, we have our employment policy Research-to-Policy Roundtable, and one of our speakers, Ellen Nissenbaum will speak a little about DI and its current challenges, in more detail.

Related to the compendium, we have a few other areas of interest. Every month we work with Kessler to release a national trends in disability employment, the NTIDE report. Again, this tides back to I think some of the work Terry had done in making sure that that information is released for persons with disabilities on a regular basis. So the first Friday morning of every month is kind of a frantic scrambling to get the data and get a press release out, including infographic, to get that out into the media.

Also new this year, we have an annual report on disability, which is a higher level progress report. I would like to thank sue Stoddard and Lewis Kraus for spearheading this. It is a synopsis of the compendium. It includes national trend charts as well as maps to depict state differences in different areas.

I just wanted to show you an example from the annual report. We've created a slide deck that we'd like people to really access and use and feel free to use the slides for your presentations you might do elsewhere.

So as an example, on our webpage you can get to this, it's on our event page right now, the 2014 disability statistics annual report slides. It's also on our compendium webpage that you can download these and look at health behaviors, employment, different areas that are included in the compendium. There's a lot of nice, pretty maps that are always effective, I think, in presentations, showing some differences between persons with and without disabilities.

So this is one other example of a map that's included in the annual report, looking at poverty and how that varies by state. This is the percent of people with a disability in poverty by state. So you can understand the patterns in the nation.

So to access the compendium you can go to www.disabilitycompendium.org. We have accessible PDF and accessible HTML. We save limited print versions. Although, I think we have hundreds. So feel free to take as many as you'd like to, so penny doesn't have to ship them all back to UNH.

We have technical assistance available at our toll-free number, 866-538-9521. As well as Relay, 711. Then an e-mail, disability.statistics@unh.edu. This is all free-to-you technical assistance if you need it. Feel free to be in touch.

I'd like to conclude just by showing our contact information for Andrew Houtenville and myself. I'll be here all day if you have any questions, feel free to grab me during lunch, once get a chance to look through the compendium and/or annual report or slide deck.

>> We do have one question online. Can you go over how taking the data at the county level is really tricky?

>> Debra Brucker: Yes.

[Laughter]

Just because we have smaller sample sizes at the county level, so it's not always possible to provide data down to that level of detail, particularly for subpopulations like persons with disabilities that are a smaller portion of the overall population.

Any other questions?

So next I would like to introduce --

>> Sorry, a question. This might be for later in the day, but two questions. Is there any consideration of looking at the population that are residing in facilities? I know that's been a question for many years.

Secondly, is there anyone starting to do a study on the causation for the 40% gap that's been pretty consistent for many, many years? Is there any consideration about the causation for that?

>> Debra Brucker: For your first question, you're right, it's difficult because a lot of the surveys that we use are household based surveys, so they do miss people in institutions and we recognize that's a gap. That's why we're very specific in all of the tables that we label that there are civilians living in the community, so people don't make the assumption it covers everyone.

Your second question is a very long, involved question that we can talk at lunchtime, but there's a lot of research that looks at the cause for the gap and whether it's related to individual characteristics of people looking for jobs or it's related to the employer, or it's related to discrimination, it's related to the educational level attained by people looking for jobs, or personal choices, or many things.

So if you'd like me to point you to the research, we can talk later on.

OK. So I would like to introduce Mark. I see he is here, which is good. Mark Perriello is the President and CEO of the American Association of People with Disabilities, the nation's largest disability rights organization.

>> Mark Perriello: Good morning, everyone. How is everyone doing today?

>> Fine, thanks.

>> Mark Perriello: The coffee hasn't quite kicked in, I think.

>> It has.

>> Mark Perriello: Has it?

[Laughter]

So welcome. This is the sixth year we have held this in conjunction with the University of New Hampshire. First, I really want to thank Debra and Andrew from UNH for all the work that you all have done, along with your team, to make this possible. Good statistics drive good policy, and this compendium is such an important tool for so many people in the disability community who are policy making. So I really thank you. My hat is off to you.

Thank you to Henry Claypool and Eva Lomana from the team at AAPD, who have been working alongside folks at UNH for quite some time to make this all possible.

Thank you to NIDRR for funding this evident. And thank you to the other partners as well, Mathematica, Kessler Foundation, the center for disability and public health institute, and CSAVR.

We really came together as a coalition to put this compendium together, and as I said, I really do believe that good statistics drive good policy, and that is why we are all here today.

One of the things, this is my third year that I get to stand up behind this podium and comment on these statistics, and I'll let you in on a little secret, I don't get to see the statistics beforehand, so I'm learning along with you all what the numbers look like. And there aren't a lot of surprises, usually. This year is no exception, unfortunately.

You know, there was, I think, a silver lining in the gap between people with and without disabilities who are unemployed. That is a silver lining. I wouldn't say it's the trend yet. It's the first year we've seen it. So more work needs to be done.

The thing I'm really struck by is really just how static these numbers have been over the years that I've been here and the six years we've been doing this. So what I would really ask folks to do is think of what they can do differently in their work to help drive real meaningful change, so that next year when we talk about these numbers we can talk about progress, and we can talk about real change in the lives of people with disabilities.

At AAPD we're looking at doing things differently, because I think it's a day whose time has come, and so, for instance, because if you keep doing the same thing over and over again, it's time to try something else.

For instance, one of the things we launched this year is the disability equality index, with our partners at the United States Business Leadership Network. This is basically a tool that fortune 1000 companies can use to assess how they're doing on their disability inclusion practices. I'm really proud to report we had a pilot process for this event, for this earlier this year, and we had 50 companies participate, and we are now launching the official disability equality index. We have 84 fortune 1000 companies that signed up to participate in this first annual survey. That is really, really significant. Because what it suggests to me is that there is a real hunger out there on behalf of employers to figure out how to do right by people with disabilities, how to get people with disabilities into their workforce and making meaningful contributions to their bottom line.

So that's a new tool, something we're doing different than before in order to drive new results. So it's going to be slowly, right, 84 companies aren't going to change the world, but it's a start. One of the things that is just true, I don't know how much people now about my background, but I did a lot of work in LGBT advocacy before I came to AAPD, and they have a tool called the corporate equality index, which rates companies on LGBT practices, and this tool, the Disability Equality Index, was a direct sort of result of my experience working with that tool, and seeing the change that it helped create within that community.

I feel like there is just as much potential with the DEI to create real, lasting, good, positive change.

The other thing, Henry and his team are leading, is really a strong look at long-term services and supports. How can we decouple services and supports from employment so that people can go to work, still get their benefits that they need and not sacrifice that paycheck? Because it's a tough decision that a lot of people have to make. Henry is working with a lot of not just allies in the disability community, but allies outside the disability community, and maybe some aren't quite allies yet but we're hoping to get them there, in order to drive some real change around long-term services and supports.

Those are just two examples of what AAPD is doing that is different, that is going to drive real change and hopefully impact these numbers in the years to come. Because I think good statistics drive good policy, but the policy needs to impact the lives of people with disabilities who are all across this country, who are suffering, who are not it as free as they could be because of some of the institutional biases that exist in our current society. These are things we can change if we do some things differently.

The thing that I want to just sort of reiterate or talk more about before I hand it over to Elaine is that these statistics are about real people, and that in all of our work we really need to remember there are real people behind these numbers, and that change for these folks isn't going to come easy, but it's going to come over time.

The story that I want to tell is about a young woman who used to work at AAPD. She wanted nothing more than to go to work for a friend of mine's company. She happened to be deaf. And I sent the resume over to my friend. I didn't hear anything back. It was very obvious -- not very obvious, but if you look at her resume, she went to Gallaudet. I may have mentioned that she was deaf when I sent the resume over.

I didn't hear anything back. Usually, this person is very, very responsive, but wasn't responsive this this instant. So what we did is I called, and I called, and I called, and about three months later finally we'll bring her in for an interview.

Well, they bring her in for an interview and they don't hire an interpreter. What they have is someone on staff who signs. That's like I took French in high school and saying that I could interpret for someone who just flew in from Paris. It's not going to happen.

[Laughter]

So they end up passing notes back and forth. The interview doesn't go very well. I get a call the next day, Oh, the interview didn't go very well, so we're not going to be able to offer her a position. Well, luckily I had heard from this young woman that they didn't hire an interpreter. I was like absolutely not. You need to hire an interpreter. You need to do this right. She's a really outstanding candidate. So a few rounds of that go by, and she comes in for a second interview. They hire the interpreter. She does such an excellent job they actually decided to hire her. And she has gone on in that company and been promoted twice at this point. In really short time. Because she's such an outstanding candidate. But what's the moral of the story? When in doubt, have an employer call the President of AAPD? That is not the moral of the story. The moral of the story is quite the opposite, that not everyone does know an expert in disability policy, not everyone does -- not all these employers have someone who can hold their hand through the process, answer their questions. And there were a lot of questions.

My friend asked me how is she going to communicate? Well, there are some simple answers to that, including pen and paper. How does she have the stamina to keep up? I was like, she's deaf. What does that have to do with her stamina?

[Laughter]

Absolutely nothing. And so we had to go through a lot of those questions. Not everyone has that access.

So it's going to take a lot of work for us to make some real change in these numbers, because there are stories like that behind all of the unemployment numbers. There are people who want to work, who are able to work, who just don't quite have that opportunity for whatever reason, and we can change that through good policy, and this compendium is the backbone upon which we can really build some great policy for people with disabilities.

So if there are two things I can leave you with before I hand it over to Elaine, it is think about what you can do differently in your own work to drive some real change to these numbers, and don't forget that there are real people who are affected by the policies that we are creating here in Washington, DC and in state capitols and local communities throughout the country, and they're depending on us to make great policies so that these numbers are change, so that their lives can change, so that they can be contributing to society the way that they want to, the way that they're able to, if given the opportunity.

So thank you all for being here today for this important discussion. We have a really great day lined up. You're going to hear from a panel on health disparities for people with disabilities this morning. This afternoon, Ellen Nissenbaum from the Center on Budget and Policy Priorities will be talking about the 2014 election.

We also have great speakers from some federal agencies that will also be speaking about what their agencies are doing to try and really move the ball forward for people with disabilities.

So thank you again for being here today. Thank you to everyone who made this all possible. With that, I will hand it over to Elaine from the Kessler Foundation, and welcome Elaine.

[Applause]

>> Elaine Katz: Good morning, everybody. Thanks, Mark. What I'd like to do this morning is talk a few minutes about our 2015 national employment survey of the Kessler Foundation is a part of. I think Mark brings a very excellent point, there are real people behind all the numbers that you're going to be hearing about today. On the screen you will see a picture of a young man who is filling a pastry tin, looks like he's making cup takes, with a chef and another woman looking on behind him. That is a project we funded in St. Louis. It's called Destination Desserts from the center for head injury. People specifically with brain injury and other disabilities staffing a food truck, going out into the community and selling goods through a social enterprise.

The other picture you see on the screen is a young woman sitting at a table and chairs with a group of plants behind her and a very lovely bouquet, if you want to call it that, of it lettuce in front of her. That's our project in New Jersey called Arthur and friends. That's an employment training program that works on hydroponics for people with disabilities. There are real numbers behind everyone you see.

What I'm going to do now is talk about why are we conducting another study? Some of you may be familiar in 2010 we commissioned, funded a study for the National Organization on Disability and Kessler, powered by Harris Cole, looking at a survey of Americans with disabilities. There were two surveys that year. One unemployment, one on quality of life. There's been many, many changes since 2010, and as we embark on the 25th anniversary of the ADA, the Americans with Disabilities Act, it's really important to see where we are at this point in time.

So as Deb discussed before, we have the American community survey, the ACS, which added six additional questions in disability, but it's still really insufficient to inform research and others in the field, people on the ground who need employment, really where we are and how to help people with disabilities.

We have Section 503 that is fairly new. WIOA passed this year. It's a great imtoo, one of the best ever and the future is really bright for people with disabilities. Still, the same gaps exist. Families don't want loved ones particularly to work. We're still dealing with how to manage incentives, disincentives, going to work part time, going to work full time. Lastly, the conversation we don't always talk about is the influence of poverty in the disability field. You talk about individuals with disability tend to be one of the largest minorities in the country. We don't talk about how large minorities often live in poverty. We want to change the conversation. In other words, we're looking at a new survey that will help form and hopefully as Mark said inform policy, but also inform those on the ground.

When we're looking to put together the survey, we came up with three guiding principles, and those are the three buckets we looked at for areas of questioning we really wanted to form the survey around.

The first one is called striving to work. What that really is is that there are lots of people in our communities with disability really trying to get jobs and trying to work. What are we actively doing towards that end? Are they going to school? Are they looking at training and development? Are they going to nonprofit agencies? What are the job seeking strategies?

The second topic is looking at overcoming barriers. So what are people with disabilities doing to get into the workplace? Are they using supports? Are they using accommodations? Do they have transportation needs? What really is the way, the best way that we can get people employed?

Lastly, we're looking at opportunities to achieve employment. What are we looking at with employer practices? How effective are the support services we have within the communities? So when we went to go do a survey, we put out a request for proposal, and what we were looking at is who is the best in the field? Who can not only do the survey portion, but who can really understand employment for people with disabilities? We frankly got lots and lots of proposals. But we narrowed it to three choices. The final was University of New Hampshire, because not only are they involved in the statistic and have the support of their survey center, but they also really understand the field. We find sometimes when you are looking at numbers and statistics there are, as Mark said, people behind the statistics, and the way you interpret data and look at data sometimes is colored by your views.

For Kessler Foundation, our principal investigator is Dr. John O'Neill, our director of employment research, who is here today. Our partners at the University of New Hampshire are Dr. Andrew Houtenville, who unfortunately was not able to be with us today, and Dr. Vidio Sunyar in the Institute on Disability.

Our partner at the survey center is Dr. Andrew Smith. Besides the professionals involved with the survey, we have a number of thought leaders, a number of consumers with disabilities, as well as people representing organizations that have come together to review some of the questions, to talk about these issues and also as we begin to disseminate the information will be really key and critical.

The way we designed the survey, it's a national survey. We're touching people in all 50 states. We're looking at noninstitutionalized individuals between 18 and 64 who potentially are eligible to work. In some instances, we may be talking to their significant other or caregiver, depending on the severity of disability. Primarily, we're trying to reach those people and find out what's going on with them, why they are working, what thanks them successful, or why are they not working?

We're looking to do 3,000 telephone interviews with a margin of error of plus or minus 1.8% and surveying through cell and land lines. We've talked about using a web component. Right now, we're not really looking at that, but one of the questions we are asking the individuals we talk to, is can we come back to you and talk to you in the future?

What we're toying with now is doing a long-term survey that is very involved and costly, but we want the opportunity to be open-ended, to be able to go back to people in a few years from now, the same people, and see what changes have occurred within those individuals.

To give you a little idea of some of the questions that we're asking as we're talking about the survey. Under the area of striving to work, what are the key -- one of the key questions is you indicated that you are actively looking for work. How many resumes or job applications did you send out in the last three months? That would be a critical question to know.

Another example of a question is I'm going to read you a list of things people do to prepare or qualify themselves for a job. Did you do any of these in the past five -- last year when looking for a job? Again, it's what are people actively doing or not doing that may have an influence on their job search.

When looking at overcoming barriers, one of the questions is what method was most helpful in finding your current or previous job?

Another question is did you or do you feel accepted or supported in your current workplace? Can you give me an example of an instance when you felt accepted or supported in the workplace?

In addition to asking questions that have multiple answers, what we're also doing is collecting responses and comments. So we hope that that will provide some other kind of data and color to the numbers that we're collecting. Some of them may be stories people tell us over the phone, personal experiences. Again, it gives us a little more behind the actual hard numbers.

Lastly, the last bucket we're looking at are opportunities to help achieve employment goals. A question may be did you encounter supervisors or co-workers who incorrectly thought you couldn't do the job? Which we hear about a lot. Mark just gave you a story, in fact, when they weren't using the right tools to get at the person's right skills.

Another question may be which of the following best describes how you feel about discussing your disability with others on your current or previous job? That way we're talking about disclosure, which we all know is a very important topic as we're moving into 503 with a lot of companies that have government contracts.

So let me give you a current update where we are. The survey launched in the first week of November. It's very hard to narrow those questions down. Our initial pool had about 100 questions. We're looking for 50. We settled on 54. We're also looking for a completion time on the phone of 15 people. It's been approximately 17 minutes. I think we're in the right area.

We've dialed over 40,000 numbers. As you know, when you're dialing for dollars almost, if you want to say that, you have to make a lot of phone calls to really get the people.

We were able to complete 180 interviews. We got really, really positive feedback. This is really as of, these numbers are as of the middle of November. Our survey continues to go on, and we're hoping to complete all the information by January or February of next year. Leave a couple of months for data analysis, collecting stories, then we'll go public with the information probably no later than June of next year in time for the 25th anniversary of the ADA.

What we did five years ago, we ended up having an event on the Hill that was open to the public, where we announced the results, then we also did a media day for media interested. We did web phone calls and webinars for them.

As Mark said, it's really important that whatever you do in this arena drives change, and there's people behind the numbers. So at Kessler Foundation not only are we funding this type of work, but we're also funding innovative employment initiatives for people with disabilities. And that's where you all can make a difference in the work you do every day.

If you do have innovative ideas and projects, we will be posting on our website at the end of December our new criteria for 2015 grants, large signature grants, they're national, innovative in scope, looking for collaborative initiatives. New for next year, those of you familiar with the foundation, are employment typically focused on research population, that researchers are using, which has been traumatic brain injury, spinal cord injury, stroke and MS. We're going to open up to the ADA definition of disability, so that really any individual population that you serve is eligible.

We're also going to look at through the lens of poverty, how organizations can work with economic development groups in a creative way, start working with those groups in typically underserved populations or other groups in poverty, but don't necessarily consider disability as part of their group. So we're really interested in seeing how that conversation goes over the long term.

Again, we thank you. We appreciate everybody coming today and hearing about the statistics. I do want to give a shout-out to the Washington Center. They're one of our grantees. We fund students from New Jersey to come to the Washington Center. Students with disabilities who spend a semester in Washington working at a nonprofit agency and get college credit for it at their home school in New Jersey.

I'd like to turn the program back over to Debra.

[Applause]

>> Debra Brucker: Does anyone have any questions for anybody?

>> I understand the concept of 18 through 64 and the demographics you're looking at for employment. But given the number of people, we have an aging workforce and they may be developing disabilities after they've actually begun employment, and more and more people are working older due to Social Security guidelines, etc. Why are you not including people above the age of 64 in the workforce?

>> Debra Brucker: That's actually a good segue. I know our next speaker has some new data about disability among older Americans that she's going to share that the census is starting to collect and release, thinking about broadening that age group we look at. Some of the information included in our annual report looks more at disability across the lifespan. We have information in there about youth with disability, as well as the typical working age we think of, as well as older Americans.

Yes?

>> I've got a two-part question.

>> Debra Brucker: Hold for the microphone, please.

>> Thank you. This is Mohammed. Two-part question. One is with the Kessler survey that is going on if grants permission was considered as a question, on the impact it could have on employment or lack of access to employment.

The --

>> Debra Brucker: Can you repeat that question?

>> If there was a question on the impact of the impact on transportation.

>> Debra Brucker: Transportation, all right.

>> Right. For access to employment, whether that plays a role or not.

>> Elaine Katz: There are a number of questions on transportation.

>> Debra Brucker: I could have said that.

>> Elaine Katz: Oh, OK.

[Laughter]

>> Debra Brucker: No questions from the --

>> I had a question on who the survey sample is. You had mentioned that quotes from the 40,000 individuals. First of all, how did you get those 40,000? What do they represent? 180 of those screened in, is there some sort of prescreener?

>> Debra Brucker: We can have someone get back to you about that.

>> OK.

>> Hi, these fabulous charts where you compare one state to another on each of the various questions, whether it's health or employment or poverty, I wonder if you have different charts that you're just organized by state, so that you could look at all the different variables by state alone, compared to the national.

>> Debra Brucker: In the compendium document itself, and also online you can look at information by state. We don't have it where you can have one page that has every variable for a state, if that's what you're asking, at this point, but we can take that under advisement for next year, if that's something that you think would be helpful, like a one-pager on each state, here's the employment, health behaviors, etc. Thank you.

>> Hello. I'm one of those people over 64.

[Laughter]

I think those are good questions, because after the age of 60 the data shows from the Census Bureau about 40% of people over the age of 60 have some type of disability. I would love to see if an organization or federal agency would like to fund, maybe they have already, looking at the institutional population as to related to Olmstead and how they are looking at there are people there that should be transitioned and can be transitioned that are in institutions. We know of many people with physical and mental health disabilities that are institutionalized and can work. I'd love to see a study like that.

Lastly, I work for the office of disability employment policy, we're working with the families and work institute, with their national study of the changing workforce that's going to be coming out in early 2015. They're one of our grant programs, cooperative agreements, the Lead center. They're going to be polling for the first time a lot of people with disabilities that are working. We went through the entire survey, question by question, and found places where there could be disability innuendos there about asking why people are working part time, people that might be caring for people with disabilities, transportation is in there as well.

That's going to be very exciting, and they just published with our help and ODEP a really nice little survey on the employment, the national employer survey and what employers are doing with workplace flexibility, Employee Resource Groups and things of that sort. It's called including the talents of people with disabilities and we're very excited about that little report.

>> Debra Brucker: Where can people access that report?

>> Go on the ODEP site, www.dol.gov/odep. Look under employers. You'll find the study and our Assistant Secretary even did a blog mentioning it.

Someone asked about statistics about the whys, the women's bureau at the Department of Labor in collaboration with ODEP is coming out very soon, it's in clearance, that typical thing that the government, it's in clearance, it's about women working women with disabilities, that should be a really interesting group. The Savan group was the major contractor.

>> Debra Brucker: Same website to access that?

>> I would probably go to the women's bureau. It's not out yet. I think it is still in the clearance state. They did a whole literature review and rationale why women with disabilities have even lower employment rates than men with disabilities.

>> We were just asked if you can identify yourself before you make the question, for the people online.

>> OK. I'm Joe king, I'm a research analyst from the Department of Labor. I've worked with Carol, actually.

So I know we've been working on a lot of great policies and accommodations and things like that for people with disabilities in the workforce, but one of the greatest barriers is the attitudes, employers' attitudes. That was alluded to by the previous individual about not having the interpreters or things like that. Part of that may have been the attitudes. So how are you getting to the hearts -- how can we get to the hearts and minds of employers and changing those views about disability? That seems to be as critical of an issue as the accessibility or interpreter. Is my line of thinking correct or reasonable?

>> Debra Brucker: Yeah, I think it's definitely a valid point. I know Mark had mentioned examples related to that, and Elaine also, that it's important for us to engage with employers, educate them, help them become comfortable if they're not with employing persons with disabilities.

>> I'm Annette, I'm going to follow up on the ODEP question, since I'm at ODEP now. Is there anybody working on a survey of employers about attitudes?

>> Debra Brucker: I'm not aware of any. I don't know if anyone else is. You?

>> Mark Perriello: So at AAPD we're actually in the midst of our strategic planning process for the next three years, and a part of that is the board really would like to see a survey of employers. The DEI itself is a survey tool. So in one sense there is a tool, but we're going to be doing sort of a needs assessment with employers, probably focused on the larger companies, just based on bandwidth right now, and expanding out to others over time.

>> Hi, I'm Lisa Dirksen, with best buddies. We have a supported employment program for adults with intellectual and developmental disabilities. We just did a survey of our employers on their attitudes and expectations in conjunction with the institute for corporate productivity and project search. We got very positive feedback from our employers, that hiring someone with disability was much easier than they thought it would be. You go to go imintohire.org or go to our website as well.

>> Debra Brucker: I want to remind folks, too, we are going to have a transcript of today's proceedings. If you are missing all of these web references, you should be able to go back and find all these links later on.

>> David Hutt from National Disability Rights Network. On the Kessler survey, is there any look at wages, specifically subminimum wages and also the sheltered workshops as part of that survey?

>> Debra Brucker: I don't think so. No.

>> Leslie Kaplan from NIDRR. NIDRR funds rehabilitation research training center on employer practices at Cornell University. In answer to one of the questions about surveys of employers that RRTC has been doing that kind of research, including a survey of human resource managers across the country through sherm, and it addresses some of the questions about attitudes and employer practices that might be developing. Some of them may have been published, but I can't remember where. You can check their website too.

>> Irene from Georgetown University. I was curious about the Kessler survey, if you guys use some sort of process in developing the questions that you ask, because I know you said you narrowed it down pretty significantly, almost in half. Was there some sort of systematic way this was done and the questions that were included?

>> Elaine Katz: I just want to say we're the funders, so I'm not the doer of the survey.

[Laughter]

But that's why we can't answer all the nitty-gritty questions. And Andrew is not here today. He's really the primary person from the University of New Hampshire. What we did, the team that was putting together, including myself and John O'Neill and Andrew and a number of others, sat down and looked at all of different surveys out there, serving people with disabilities and came up with some questions. They were run, my understanding, through a panel of consumers as well. Then we narrowed them down in the different buckets and categories and tried to get the most clear question for what we'd like to get out.

It's always difficult. I'm sure there may be areas we skipped or missed, but that's how we ended up getting the questions with did. Everything was testeded. This is a statistically valid survey, so every step of the way is done with a survey center and their expertise, as well as the Institute on Disability at UNH.

>> Good morning, Paula, with the Internal Revenue service. I have a question, several questions behind. When you were doing your phone interviews and as you're conducting phone interviews, are you using video Relay service? If you're not, may I make that suggestion, that you do consider either using an interpreter or using someone that is native to the language so you get a fair and equitable survey?

>> Debra Brucker: I will bring that back to the team. I'll be saying that a lot today, as Andrew is not here. OK, one more question, then we'll move on to our next agenda item.

>> Jennifer Mizrahi from respectability USA. Didn't have a question, I want to say we released three national surveys on disability employment. Two of them are phone surveys, and the third was an internet survey. Two of them had a sample size of a thousand, the internet one had a sample size of 3800. But what's different about what Kessler is doing with you is that you have a wonderful sample that I think is far better than the internet sample that we used, so I'm really excited about that new data. If anyone wants the three surveys that we've done I'd be happy to share that. One of the things we looked at particularly is the stigma surrounding disability employment and what messages will work best to alleviate that stigma, and what we have found is that this the messages that are largely used by the pro-employment, employment first disability community are not even close to the most effective messages to reduce the barriers to employment in the minds of the public, and that there are messages that are twice as effective as the messages that are largely used by the disability community to expand employment. I would be very happy to share that data with anyone who is interested.

>> Debra Brucker: Thank you. Next we move on to our data workshop, hearing a little bit about what is happening at the US census bureau, as well as the Centers for Disease Control and Prevention. Our first speaker is Amy Steinweg. Matthew, for those who saw him in years past, is now at Harvard pursuing his PhD. We wish him well. Welcome to Amy.

>> Amy Steinweg: Thank you. So again, I'm Amy Steinweg, from the health and disability statistics branch at the US Census Bureau. I'm here to tell you a little about our data products we have related to disabilities, both things we have released in the past year as well as some things we have coming up.

>> Can you pull the mic closer to you?

>> Amy Steinweg: Absolutely. Better? As you know, the Census Bureau is a vital source of data and estimates on disability status within the country, and it is the source of many of the estimates you find in the compendium that have been organized so nicely for you in that source.

There's three major surveys I'm going to talk about today that provide disability statistics that we do, each have their own unique strengths, their own special thing they offer.

The American Community Survey, it's the long form census, we run it continuously, produces annual estimates. Its great strength is sample size. It allows us to get to local estimates, very small geography levels.

The current population survey is a survey run, co-sponsored by the Bureau of Labor Statistics and the Census Bureau. The chief strength of the survey is that this is the source of our labor force characteristics, our employment measures, and allows us to look at this across disability status.

Then there's the survey of incoming program participation. This is a smaller sample, but tends to be a much richer survey. We're able to ask more questions about disabilities. As a result we can net a broader range of persons experiencing different limitations. It's a longitudinal survey. We're able to look for a given individual with a certain limitation how they fare over several years. We can look at transitions in and out of employment, poverty status, marriage, what have you.

Then additionally, back in 1990, when the ADA was being developed, these estimates are used in developing that. Finely,ly talk a research project we're working on for modeled estimates of disability, using different data sources.

So this is all I think probably most of you know, but I wanted to review it, because what we measure depends how we measure it. Disability is complex, and what we ask, that's what we're measuring. In ACS we have six questions that we ask on disability. This is a standardized set of six questions we began asking in 2008 after many years of development and testing. The purpose of these questions is to try to capture individuals at risk of activity limitation, experience of that limitation rather than a presence of some condition that may or may not act as impediment in dimensions of their life.

These questions include hearing, vision, cognitive difficulty, defined as difficulty remembering, concentrating and making decisions, ambulatory difficulty, defined as difficulty walking or climbing stairs, self-care, defined as difficulty dressing or bathing and independent living, defined as difficulty doing errands alone, visiting a doctor, going shopping, things like that.

The American Community Survey is very large sample. In 2013, we collected interviews for over 200,000 households and over 163,000 individuals living in group quarters. As a result, we can produce estimates at very low levels of geography, and many local governments use our data for program planning and resource allocation.

These data you can find at the American Fact Finder. It's an application on census.gov. There's a screen shot behind me. There's a variety of tables you can find there as well as accessing the public use microdata. You can always contact us if you need help finding anything.

We produce a number of different statistics. We produce annual one-year estimates, as well as three and five-year pooled sample estimates to be able to produce statistics at the lowest levels of geography possible. Someone mentioned you get to very small sample sizes, it's hard to produce an estimate with good enough confidence. We really try to maximize what the American Community Survey can do with that sample.

Now, we just released one-year estimates for 2013 this past September. We released our three-year estimates for 2011-13 in October. And tomorrow we are releasing our five-year estimates, that's pooled 2009-2013 data. This data allows us to produce estimates for all counties, all places and all census, tra.

Additionally, we have two reports we're working on or have released using five-year ACS data. The first is working with the disability. This is still in process. This is going to look at 2009-2013 five-year data, and we're looking at the employment characteristics of persons with a disability, whether or not they're employed in the labor force. Among workers across disability status we're looking at industry and occupation, earnings, commuting patterns and hours and weeks worked as well.

Then there is a second report, older Americans with a disability, using the data set 2008-12, that was released yesterday. So that will be available online for you and I'll show you where to get that.

A couple snapshots of what this report shows. The report looks at a number of characteristics, including education, living arrangements, poverty status, etc., but we're going to look at geographic Director of Operations since that's a strengths of ACS.

I'm showing two different ways you can look at that Director of Operations. One of them is the total number of older Americans with a disability, older, 65 and over is how it is cut. What we see is when looking at the total number in the country, that about half of that population is in only nine states. The top of that is California, Florida, and Texas. Obviously, that is some implications when thinking about budgets and whatnot, but demographically that's a little less interesting because it's not surprising these are our biggest states, so the biggest total population, biggest older American population.

Then the other way we can look at it is the proportion among older adults, what proportion are experiencing a disability or functional limitation. So this map in this picture we're showing it by the county level. Of course, what we find is a very different pattern. In California, that state with the most older Americans with disability, the proposition is actually about the national average. Instead, we find a different Director of Operations across areas such as central and north central Appalachia, the Mississippi Delta and certain American Indian reservations in Arizona and New Mexico.

Now, there's the current population survey, referring to the monthly basic survey co-sponsored by BLS. Within here, they ask the same six questions that have been stated by ACS, added in the interest of harmonizing disability measures across government surveys.

The universe is a little different, because this survey focuses on labor force characteristics. We're asking the civilian noninstitutionalized population 16-plus. We're not getting children. And again, the real strength of this and why it was long lasting is we need to be able to look at employment rates and labor force participation. So this allows us to look at disability across these characteristics as well as income and poverty. Every year when the census puts out their annual health insurance reports, income and poverty reports, these are the disability measures we're using.

So prior to the addition of these questions, the questions that were available in the CPS, there were questions that collected aspects of work disability. So given the data available the census did produce a drive to variable looking at data within questions, two questions from the CPS basic, five questions from the CPS annual social economic supplement. Brought that information together into a produced variable of work disability. So they produced a number of tables, beginning in 1995 to show these characteristics. However, there were two big limitations. The first is that these questions were not designed, were not tested to measure disability or work disability. It was a posthoc thing, trying to leverage the information we had. The second is that we weren't capturing disability broadly defined. We were capturing work disability. A chief concern is we need to measure employment among this population, and when defining it as work disability there's a conflict between health or condition and your ability to work, then we're buyaing estimate of labor force participation and labor data and we're not getting what we need.

In June 2008 the CPS added these questions. It was wonderful. Terry worked very hard on that, and it's been a beautiful addition. After 2008, given this, the census stopped producing new tables with the older work disability measure.

A third survey is the survey of incoming program participation. Some of you may know it was recently redesigned, beginning panel 2014. It was a significant redesign. We're going into the field once a year, instead of three times a year. Instead of collecting four months of data at a time, we're collecting a calendar year of data a the a time. Using event history calendar to help cap HR that longer -- capture that longer reference period, hopefully not too many recalled issues. So far the test data is doing a good job.

We asked disability questions within the survey. We asked about a dozen questions each wave. We asked the six standard ACS questions. Also children under 5 we have an additional question on developmental delays or conditions that affect their ability to do normal activities. Children ages 5-14 we asked two questions on whether they had limitations and their ability to play with children their own age or do their schoolwork. Adults 50 and plus, three questions getting at work disability. There's the classic are you limited in the work that you can do? We also ask whether they had difficulty finding employment or remaining employed. Then if they're prevented from working altogether.

So we have already collected this data. We're working very hard to process it now, which is quite a large project the first time you have a complex redesign survey. We are anticipating our first release of the data file in summer 2015.

In addition, in the past in SIPP there were a number of top cal launches. We fielded at periodic intervals to capture richer, deeper disability information. So we asked questions on work disability, work disability history, adult job function limitations. Unfortunately, these are no longer asked beginning if 2014. How, we have a supplement that has been sponsored by the Social Security Administration, and that will be fielded in wave 1. It has already been fielded. We brought together many of the great questions from the different topical modules we've asked.

This is all administered by telephone. All the sample in wave 1 we're going to come back and give in a smaller survey. There's a number of different topics that you can look at the data across these topics as well as link to the core data.

I jumped ahead myself a little bit. We're combining all these topics together. One really neat enhancement is how we're capturing the health conditions underlying the work limitations, the functional disabilities. This was something that was developed under Matt, that I think is really quite brilliant. In the past we'd ask what was the health condition causing your limitation. There was a list of 29 conditions and 30 other. There's an interview in the field, they're trying to get through the interview, trying to figure out where to code that specific condition they gave them. We're getting a lot of other. It just wasn't very functional. As a result, the data wasn't so informative.

He developed now the instrument we're asking the interviewer to type in the condition as it was reported. They type in three letters, the instrument types up a shorter list of condition with those three letters in it. It is out of a total maybe 400 conditions the instrument is storing. They can choose the precise condition. It is linked within the instrument to a code to help with data processing. As a result, we're anticipating much richer, more complete data on underlying conditions, which is very important to talk about what's the EDI, just a variety of implications, the health condition underlying what they're experiencing.

This data we anticipate our release in December 2015.

Finally, we have a research project as I mentioned working on small area estimates, and what this is doing is thinking about the data we have and what can we -- how can we leverage it to get the most information out of it. Looking at the two surveys on the opposite ends, the ACS with this vast sample size, low levels of geography, but six questions, which are great, but maybe we want to know more. On the other side, SIPP, much more small sample, but an itch arer way of -- a richer way of questions. We have researchers at the statistical research and methodology center at the Census Bureau, they've been investigating this, they're using those two different data sources along with some auxiliary data, such as administrative records, and they're using statistical modeling to try to produce small area estimates. When I say small area, I'm at county, state level. They've used two different approaches. One is to model the area estimate directly. The other approach is to try to predict, to model disability status for individuals. Then treating it just like you would reporting microdata from that, you can produce estimates at the desired area.

So far there is results on their work at the area level model and there will be a link to that on the next slide.

Here is where you can find more information. There's the home page for disabilities at census.gov. There's a few links for American Community Survey. It takes you to fact finder. Again, tables with that microdata. Then some links to the report that just came out. As well as two links on the small area paper.

Now, I should say the older Americans with a disability, this link is not in the copy of your slides, on your thumb drive or online, because it was just released. We just got this link. However, we're working to get it available through the disability webpage. Hopefully soon you can go to census.gov, disability, publications, you will see it on that list.

Finally, there are links for the Bureau of Labor Statistics. Here is where you can find more information about the CPS disability products. Links to the latest news releases, tables, great figures under the economics daily. Then some more information about the development of the questions, some background on it, certainly a lot of work that Terry did.

Again, my name is Amy Steinweg. This is my contact information. I'm very happy to take any questions going forward. Feel free to contact me. I will help you get ahold of what it is that you need. Thank you.

[Applause]

>> Debra Brucker: Where's our roving microphone? One question. Is it for Amy? Do you want to come back?

>> Amy, that was terrific. I have a very specific data need, which is that as WIOA is being implemented, every state by law must create a unified state plan for increasing employment for people with disabilities. The Mathematica data shows that the best outcomes are coming in transition from school into work. So I'm wondering on a state-by-state basis what do you recommend as the best places for them to receive data that will ind indicate their talent pipeline?

I know that you have a category 16-20, and it does show by different category of disability. We've looked at the Department of Education in terms of IEPs. What do you think the best place is for the states to look for what is their talent pipeline of young people with disabilities coming into the workforce?

>> Amy Steinweg: At the state level, the ACS is really where it's at, which I guess the limitation is it is cross-sectional. You're not showing change over time. So I think that's what you're talking about you've looked at.

The SIPP, I haven't seen the final sample size or recommendations in the past you've been able to look at it for some states. For the larger states there would be enough sample to produce estimates worth looking at. Usually it's used at the national level. So if that's the case within a sample, that may be a way to actually look at transition, at least within those states.

So when the time comes, certainly, if you want to get in contact with me, I'll speak to the survey director, whatever is appropriate, to find out the data on that.

>> Mark Perriello: Could you clarify what questions are not going to be asked in the future? I think you mentioned some things are not going to be asked.

>> Amy Steinweg: I realize too for the last question, I believe the CPS can do some state estimates. But again you're having mostly cross-sectional.

Within the SIPP, you can say we are losing some questions from there were topical modules in the past, three or four work disability. So a great deal of that content we have preserved in the supplement we're doing that we have already fielded. I don't have a list of exactly what is in or out. Certainly, I can research that for anybody who needs to know.

Offhand, I couldn't tell you what specific questions were dropped.

>> Mark Perriello: Is that common for the questions to change?

>> Amy Steinweg: We try to preserve things as much as possible. In this case, we fielded the same questions over and over, but it's such a large restructuring of the SIPP it is a cost effective things bimoving to the year level, because going out in the field over and over is a massive human labor outlay. We had to make adaptations. In general, we try to preserve continuity. We understand the timeline is really important.

>> Hi, Jean with Mathematica. I was wondering in the new SIPP, the 2014, are the sample sizes for people with disabilities and in particular Social Security beneficiaries going to be large enough to look at them as a subgroup? I know in the past SSA has funded oversampling of that group, and I don't know about the redesign if those sample sizes will be so small that we couldn't look at them as a specific population, which we do a lot of in our work at Mathematica.

>> Amy Steinweg: I guess the answer is I don't know until I see it, right? We're still processing it to see the final numbers. It's my knowledge that we didn't specifically oversample the population with disabilities per se, that the supplement went to everybody. Now I believe SIPP does try to oversample sort of disadvantaged groups, then of course weighed it to the population level. So to the extent they did that at this time, we will be netting going forward.

>> David, Mathematica. It's related to Gina's questions. When you're -- I have two questions. The first is dealing with the Social Security supplement that you have. Are you going to be using monthly administrative data to identify those populations? Are you going to identify people based on their self-report of Social Security benefits. That's my first question.

Second question, a testing question. Given that you're moving to an event history framework, and employment of people with disabilities tends to be more episodic, do you know if there's been any piloting of the questions in terms of what we might expect in terms of employment rates, how they might change in an event history framework versus what we've seen previously in the SIPP?

>> Amy Steinweg: The latter request he is freshest in -- the latter question is freshest in my mind. There has been testing. I don't know that any has focused on unemployment. What we've looked at validating was the concern is we're going back farther in time, and are we going to have low recall of past events. There was research where we had added records, topics where that applied. So I don't know that we were able to leverage that for the employment characteristics. But we are, by design, trying to catch churning, we're trying to catch moving out transitions. That's sort of the name of the game. So we did, but again, going back to your first question, this is self-reporting. If they don't recall, if they don't tell tus, we don't capture it. To my knowledge, what we're doing with the SSA supplement we're not bringing in added data. What SSA is planning on doing, I would suspect they would as part of their research. But we're asking them to report as we're passing that data.

>> Debra Brucker: Thank you, everybody. In the interest of time, I'm going to have Brian Armour come up from CDC.

>> Brian Armour: Good morning. Good morning, everyone. Can you hear me OK? OK. Great. My name is Brian Armour. I'm from CDC. I'm kind of, I've always felt a little like a fish out of water at this event, because the focus is really labor and employment of people with disabilities. I'm here to talk about health. But there's a colleague at CDC who likes to say that without good health, employment is difficult. And what I've shown over the years here I think is that there are tremendous opportunities to improve health and wellness for people with disabilities, particularly those of working age, 18-64. I understand that there are folks these days also working older. Although I'm trained as a library economist, that's a little difficult, because in labor economics we think of labor as not a good thing. We think of leisure as a normal good and labor as inferior good.

[Laughter]

This meeting is always a little amusing to me.

The other things I'd like to say, I'd like to thank Andrew and Debra for inviting me, keep inviting me back. I guess I must be OK. I have gotten to know Matthew, looking forward to getting to know Amy a little bit. I got to know Terry really well. As a fed, we're limited in what we can do at this meeting. For instance, I did not touch the food.

[Laughter]

I just can't touch it. Terry and I would actually disappear at lunch, we'd go somewhere to eat. That's where I got to know Terry. I'm really going to miss Terry. He was a real -- he was an economist, but an advocate for people with disabilities. He will be dearly missed.

Without further ado, I'll move forward here. OK. I'm taking a little risk today. Usually I get up here and talk about something that I'm really passionate about, and I'm working on, then the plan is come back next year and talk to you about how it kind of evolved. It usually does evolve. But today I decided, I'm going to interview CDC and decided to talk about some of the projects within my division. I'm not really that familiar with some of them, so I had a bunch of folks in this slide help me with the different data systems. These are data we disseminate at CDC. We disseminate publicly. Some are kind of in the works, but some you will be familiar with, some perhaps less familiar with.

The first two are really national. They're state-level data we collect and disseminate. You may be familiar with, I talked about the first one several years ago. It's a really neat system that shows opportunities to improve health and wellness for people with disabilities. The others are rare disorders, spina Biff idda, fragile X, muscular dystrophy. I'm less familiar with those. We go from millions records to kind of hundreds of records here. Also I'll talk about some work on the diagnosis and treatment of ADHD and also Tourette's.

First is disability and health data system. This is a source for state-based data on the health of people with disabilities. We use our data, information in every state. What we pulled together, it's kind of a map-based system. It is information on 80 health indicators for people with disabilities. We call it surveillance. Some people see that as a bad word, but in public health we think of health surveillance. That's what it does.

For every state, you can look at these maps and click on the maps, they're interactive, figure out mammography screenings, smoking, you can compare people with disabilities to those without, hypertension.

There's also payer information on the system. What I want to talk about are some developments to this. We've recently added the 2012 data, and also I want to say in 2013 we have the ACS questions, at least five of them. We don't have the hearing impaired question. Our telephone survey calling up someone who is hard of hearing or deaf is, some of our lawyers think that's problematic. That's the challenge, but we've got five to six ACS questions in 2013, and hopefully I will talk about those next year.

What we have with the 2012 data added in July, disability data by demographics groups, not available for all indicators. There are 80 health indicators in there. We have P values with significant differences, and these dual area profiles. The lady there, I'm sorry, I forgot your name, you asked about if there was one stop shop where you can look at a bunch of indicators for states. Well, on this system you can. But you can also compare it to states. You can compare New Hampshire to the state of Vermont or any two states in the country. You can look at I think about 20 indicators, 20 health indicators, and look at people with disabilities and compare to people without disabilities also. It's a really neat additional feature.

Also we have it on mobile devices. We have standard and high contrast views for those with vision impairment. It can be viewed on any Smartphone or tablet, as long as you have explorer 8 or earlier.

This system is really in-depth. It goes back to 2004. We've got data through 2012. You can looks at trends. It's a little complicated. We have tutorial videos available, with the introduction and interactive map, customizable data table and state profiles. You can get this at cdc.gov. You can also go to YouTube on these will pop up.

The next data that we disseminate is early hearing detection and intervention data. This is data we use, it's in 50 states, six territories and the District of Columbia. It's to ensure deaf and hard of hearing are receiving diagnosis and intervention services. We make sure these kids hopefully reach full potential.

Here's an illustration of the information that we collected. Again, this is all available at the state level. We're giving it overall for 2012. There are about 4 million births in 2012. 3.8 million kids were screened for hearing loss. That's states, territories and DC. But 52,000, approximately 53,000 failed screening. Of those that failed screening, approximately 5500 had a hearing loss. 23 thousand no hearing loss. We diagnosed about 30,000, and you can see that there's 24,000 of children who either died, moved or somehow lost in follow-up. There's opportunities here to improve what we do with this program.

If you want to learn more about this program, visit CDC and the supplement. It talks it more about it. Afterwards, I can direct you to that supplement. I also want to talk about future work. These are added programs, the link. We continue to support states in enhancement of data. With all of the hospitals now, the electronic medical records, we're doing a lot of work with interoperability, making sure that when things go electronic that that information can then be used by us. They're also trying to develop ways to analyze access, better access progress on how that occurs. Again, 24,000, we'll be thinking about that a lot.

Another program, I'm going from hundreds of thousands of records with DHDS system each year, millions, to now hundreds of records with these conditions, what we refer to as rare conditions. We have a spina bifida program. Most common permanently disabling congenital condition in the US. We think there's about 70,000 Americans living with spina bifida. But we're not sure.

It occurs in about 3.4 per 10,000 life births. So the limitations to the current research, that's our best guess how many people have spina bifida. There's few research multisite studies, few randomized control trials. Few long-term treatment outcomes for spina bifida. We gather a lot from clinics, facilities that treat people with spina bifida, set up specially to treat them. We find there's a lot of variation in these programs in terms of structure of services, staffing and care delivered.

What we're trying to do at CDC with the spina bifida association is establish a patient register, identify best practices for spina bifida care, implement use of a shared electronic reporting system, help support clinical research and systematic approach to improving the quality of care, compare spina bifida patients among clinics to see if there is variation in outcomes and quality of care. Then guide and help prioritize future research areas.

This is an area I worked in a little bit.

You it's been exciting to see it grow. In 2009, we had about 10 clinics. Currently, we fund about 14.

We have longitudinal data on over 4,000 patients. There are a couple papers here with about some of the work. We've done not a lot, but work around UTI, which is fascinating to define. And looking at future work, including pressure ulcers, which is problematic for people with spina bifida.

This is a mouthful. This is the forward database, or the fragile X online registry withble accessible research database. It's the most common known inherited cause of ID, intellectual disability. Estimated prevalence is about 1 in 4,000 to 5,000 males, about 1 in 6,000 to 8,000 females. We have no idea how many people have it.

People with FXS show a range of intellectual disability, and they also experience emotional, behavioral, sensory as well as social difficulties.

We really need the information to kind of enhance our understanding of FXS. It's co-occurring conditions and identify service barriers and needs, determine the effect of current services on health, and document medical and behavioral treatment use and efficacy. That's what we're trying to do.

We support this consortium to try to implement this forward. What really this database is, it's a registry but also longitudinal database. We did a pilot study in 2008-11 and collected data on 276 individuals with full mutation FXS from nine clinics. This currently we have information about 2,000 individuals, and over 500 with full mutation FXS, and we've drawn the 25 clinics, but now it's back to 24. Currently 24.

This data is available for folks to use. If you go to www.fxcrc.org you can find more information how to access that information.

OK, this is our MD STARnet, muscular dystrophy surveillance tracking and research network. This varies by age of onset, muscle groups affected, genes involved, severity and progression of disease. What we need is population-based data to again estimate the prevalence, mortality and prescribe access to care and treatments.

Our objectives, to characterize prevalence, natural history, healthcare use and costs and disparities in access to care. And assess whether specific treatments, interventions or changes in healthcare use are associated with the disease progression and survival.

We obtained data from two sources, medical records and administrative data. The medical records come from hospitalsened a the clinics. The administrative data from birth and death records and discharge and information. We do interviews and surveys.

We started data collection in 2002. We looked initially at Duchenne muscular dystrophy. Now we look at all beginning if 2011. Again, a small program. Funded in six sides, a couple states, then some areas in states.

We also look at longitudinal data collection. With this data, again, we hope to look at geographic Director of Operations of individuals with each type of MS. Highlight similarities and differences in treatment, morbidity and mortality. Provide information to services providers, advocates to improve decision making.

There's a lot of information coming out. If you are interested, I can direct you to some articles on this topic.

I feel like I'm speed reading here, but I have 10 minutes to get through this. Bear with me.

We have a child development studies group that focuses on ADHD, attention deficit hyperactivity disorder and Tourette's syndrome. That's mental health and other things. These are two things they focus on. ADHD is typically staying focused and paying attention, controlling behavior over activity. Childhood onset, often lasts into adolescence and adulthood. 6.4 million children aged 4-17 years, 11% of kids in that age have a diagnosis. With Tourette's, it's motor and phonetic tics that persist for less than a year. Severity is typically between 10-12 years. 95,000 children in that age range have Tourette's syndrome.

We get our information, back to the national surveys, I'm trying to pull information from national surveys. The national survey of children's health conducted from age 7 and 11 to 12, provides information and prevalence of diagnosed ADHD, medication, treatment, and diagnosed Tourette's syndrome. Then the national survey of children with special healthcare needs, 2001, 2005, 2009, provides information on ADHD treatment, including medication, behavior therapy and dietary supplements. One of my colleagues is doing a lot of work on this, sue Visser, you may have her about it, because of the medicating of kids who are very young with ADHD medication. There's a lot of good work going on here. We also do other projects, and I will skip those in the interest of time. We also do a lot of work there.

The highlight what we're doing around this, what we did was, or what my colleagues did was, they followed up with everyone identified in the national survey. Of children's health, I believe, 11-12, to investigate diagnostic context for ADHD and/or Tourette's syndrome with co-occurring conditions, treatment types, adherence, academic health and discipline, and family impact of ADHD and Tourette's. Here are key papers. If you have a chance to have an opportunity to look at them.

There's my contact information. Again, I felt like I went through this, I'm familiar with some of it, not all of it, took a little bit of a risk here. But I wanted to get tout there what we -- out there what we collect, what we do. I think hopefully some of you will be interested in it. Please follow me afterwards. Again, keep in touch with folks who do not know a lot about some of these conditions. Thank you.

[Applause]

>> Thank you. On the work you are following, I wrote down several. Are you following other NORDs or are these other ones?

>> Brian Armour: NORDs?

>> National registry of rare diseases.

>> Brian Armour: Are we following others? These are ones that I highlighted. I'm not sure. We could be. There's lots of colleagues that can do lots of things. Sorry. Let me follow up on that for you. I don't want to say yes or no, because I don't know. Let me double-check. If I can get your card, I will follow up.

Is that it? Thank you.

>> Debra Brucker: We have a little bit of time built in for questions related to the data workshop or any of our prior visitations. I feel like we fit those in throughout the morning. If we have any questions remaining, feel free to find any of us during the lunch break.

I'd like to bring up now our disability and rehabilitation research project health and healthcare disparities team. Which was supposed to be four people, but due to some jury duty and flight cancelations and things, it is now two people. So they're going to cover the presentation. First is Monica McClain.

>> Monica McClain: Thank you, Deb. I'm presenting this morning on behalf of Charles Drum, who is the principal investigator of this project, and I know that he is very disappointed not to be here in person, and so I will present the introduction to what was supposed to have been the four-person presentation. I will be talking about the disability and rehabilitation research project, healthcare disparities among individuals with disabilities.

The overview of the introduction will be to go through the acknowledgments, give you a brief background on this project, introduce the two panel members.

[Laughter]

So this project was funded by NIDRR, also collaborated with the Research and Training Center on Community Living grant.

The expert panel for this project was comprised of Glenn Fujiura, Gloria Krahn, Elena and Charles Drum.

So the core project team is spread across two institutions, at the University of New Hampshire decides myself and Charles and Amanda, who will also be presenting, Andrew Houtenville, Michelle transky, Eric from the Institute on Disability, and Bob Mcgraph from the Department of Health management and policy at UNH.

The primary members of the Oregon health sciences university research team included Willie Johnson, Emily Walsh, Conrad and Mira rouland. Then Janet Peterson at Pacific university. Additional project staff from the University of Kansas including Glen White, Megan O'Brien, and I'm not sure about the pronunciation, Emily Marovkulik from Kansas.

The project need, this is the background of the RFP to which this project responded, was showing growing body of research on health and healthcare disparities experienced by persons with disabilities. And more importantly, to drill down into the types of disability or the different disability groups, and to look at the disparity factsors that might exist in the subpopulations of people with disabilities. Then some of these factors include those at the systems level, some examples listed there, the environmental level or the individual level. There will be additional information about these factors later in the presentation.

So this was a multipronged project. There was a systematic scoping review. Two of them, which looked at health outcomes among disability subgroups, and healthcare utilization among disability subgroups. That will be the presentation that I will be giving you in just a moment.

Scoping reviews are a method for evaluating what literature exists about these topics, and then presenting that information. It can be used to inform research. It can also be used to determine if there's sufficient literature to perform a full systematic review.

The second approach was secondary data analysis using the MEPS data, medical expenditure panel survey. There were two different groups of years included in this analysis. The factors that relate to health and healthcare disparities among different disability groups. That will be the second presentation.

Then the policy recommendations that were derived from the MEPS analyses. Usually, scoping reviews don't result in policy recommendations, so that those will not be -- there were no policy recommendations from the scoping reviews. And there will be then question and answer.

So I am Monica McClain, I will be in addition to introduction summarizing the scoping reviews. Amanda Reichard is my colleague and will be talking about the MEPS secondary data analysis. And Kimberly Phillips also was unable to attend. She was going to do the policy recommendations, which Amanda will cover.

So I'm a research associate professor in the Department of Health management and policy, in addition to being at the Institute on Disability at UNH. I am with the New England genetic collaborative, one of seven funded regional genetic screening services collaboratives. Also the PI of the New England critical congenital heart disease newborn screening project. The focus has been on evaluation and implementation of evidence-based practice. I also have a background in systematic reviews. My training is in the area of epidemiology and so collating and analyzing data is kind of my thing.

Since I've come -- I came to the IOD in 2010 and expanded research to include health disparities research among people with disabilities.

Amanda is research assistant professor. She received her MS from the Harvard school of public health, and PhD from the University of Kansas. Dr. Reichard has been the PI or co-PI in a feel initiated research project and received funding from the Centers for Disease Control and Prevention and the National Institutes of Health, among other agencies. She conducted research in a number of areas, including barriers to accessing healthcare, health disparities, chronic conditions, disability, obesity interventions for persons with intellectual disability and disability awareness interventions for medical and dental professionals.

Dr. Reichard will an rise the data that summarizes the maps.

I will now summarize the two systematic scoping reviews from this project. I'll summarize each of those, and the citations are included there. They're also in your bibliography.

Again, what is a scoping review? They're a systematic way of assessing the literature in the particular topic, and there is -- it says rapid gathering, but usually it's not so rapid. Usually it's very time-consuming. To summarize the literature. And see where the gaps are, if any exist, and to kind of synthesize and summarize the information available in the literature.

So this is the -- I'm sorry, my slides got out of order. This is the review process for scoping review. You start off by framing a research question, and that kind of informs the literature, research you're going to do. Develop inclusion criteria. Then you actually have to search the literature to find out what literature exists on that area.

You select your studies based on inclusion and/or exclusion criteria, then extract the data. The result is that you map the literature landscapes. You analyze, look, see what is known and what isn't known from the literature. Then you kind of try and interpret and disseminate that information.

The first review, and I don't want to confuse you, I saw that one of the previous speakers used CPS as an acronym for the survey. I will be using the term CPS to mean clinical preventive services. I apologize if that is a little confusing. The key question here was to examine clinical preventive services' use, disparities among groups of people with disabilities age 18-64. So this was the key question. The inclusion criteria was that it be in English language, published between 2000-2009, the study was conducted in the United States, and the original research was published in a peer review journal.

Adults with disabilities ages 18-64, the use of clinical preventive services and comparison by potential disparity factor.

Then to identify those studies, it included doing searches on med line, psych info, then table of contents for predetermined journals were also reviewed to look for these articles. Then the reference list from those articles were also reviewed to see if there was any other literature that could be identified.

Then from that process there were 4160 abstracts that were screened. Of those, 107 went on to a full text review. 27 articles were included in the final analysis. So as you can see, it's not a rapid gathering. It's usually very tedious. This one involved over 4,000 citations.

The numbers are there. Sorry. I didn't realize those were in the slide.

Here again are the potential disparity factors that we're looking at. You can see there aren't just a few. There are many.

So we're looking at articles that included information about any of these factors.

This slide is a little bit busy. To orient you, the clinical preventive services are along the problem. The X axis. I'm not sure how the font is showing up for you here, but the examples are mammography, clinical breast exam, cervical cancer screening, cholesterol testing, tobacco screening, alcohol screening, exercise counseling and nutrition counseling. Those are on the lower axis.

On the Y, or the vertical axis, is the number of studies. Then the colors represent the direction of the evidence. So the first bar is the blue bar, showing there is evidence of a disparity. The grayish middle bars are showing that there is a mixed evidence. Then the orange bar is showing there's no evidence.

As you can see from are the first group under mammography, there were three articles that showed a disparity for people based on disability severity. And receipt of mammography. Two that had mixed evidence. One that showed no evidence.

Then you can kind of see how that carries out for the other clinical preventive services across the spectrum.

So it's quite a heterogeneous group or results from the literature.

Disability severely was not consistently defined among these studies. It's a little like comparing apples to oranges. Some of the studies used the activities of daily living, and the instrumental activities of daily living. Some of them used scales created from answers to multiple disability questions, and we're categorizing them as mild, moderate and major difficulty. Some were categorized by using fully ambulatory, ambulatory with help, and not ambulatory. For the studies that do show a disparity, they showed that the more limiting disabilities, those people with more limiting disability were less likely to receive these clinical preventive services. Again, you can see that this really isn't consistent across those studies.

Now this is looking at the disabling condition. So the disabling conditions were defined as a mental health disability, physical disability, sensory disability, intellectual disability, developmental delay, or cross-disability, which means they had various functional limitations.

Again, you can see that here there are gaps. There are not studies of each of these areas, and fewer preventive clinical services on which there is literature available.

Here again, now we're looking at insurance. You can see there's really sparse data. The CPS in general, these studies had a list of clinical preventive services. If a person received any of them, that was counted as yes they received them. Or if they -- how many preventive services they actually received. Again, there was variability in the definition of what a -- how they defined receiving a clinical preventive service. Again, sparse data. These remaining slides, again, are showing the sparsity of data. Here is looking at age and the directionality of evidence or not consistent, ethnicity.

So the results of this scoping review show there are many gaps in the data, both on the clinical preventive services, but also the types of disability and the disparity factors. There were variety of research methods using these studies. There was a heterogeneous definition of disability. And the directionality of it the evidence was not consistent.

The second health scoping review is on health outcomes, and there is your key question. The inclusion criteria were the same as for the first one. Except for it was looking at health outcomes associated with the 10 leading causes of death. Just for those who don't know those by heart, I will list those, so you know what we're talking about, heart disease, cancer, vascular disease, respiratory disease, accidents and injuries, diabetes, Alzheimer's, influenza/pneumonia, kidney disease and sepsis. These are any articles that looked at any of those conditions.

The identification process was the same. The literature review, tables of contents and reference lists. And the outcome was 4228 abstracts screen, 239 full text articles were reviewed, and there were 29 articles included in the final analysis.

The scoping review did not assess directionality of evidence. So the graphs will look a little different.

So there is no directionality of evidence on the X axis, the horizontal axis are the health outcomes, or leading causes of death. The left are the Y axis, the number of studies.

Diabetes had the most number of studies at 10. Respiratory disease 4. Others, the rest in that list there were no articles that looked at types of disability and these leading causes of deaths and disparity factors.

Again, this is showing again the paucity of data. There were for disability severity only two health outcomes that had literature around those. Age, same thing, there were two. Gender there were a few more. Race/ethnicity a few. And socioeconomic status, education income, just the one health outcome.

So again, many significant gaps in the research, and on health disparities among people with disabilities, and the heterogeneity of the populations and factors study.

So the recommendations for health disparities research is that there should be more rigorous methods for studies that are conducted. It would be helpful to have clear and consistent definitions of disability and disability severity. And then identification of individual characteristics associated with the sub-optimal receipt of CPS and adverse health outcomes.

Thank you. I will turn it over to Amanda.

>> Amanda Reichard: Good morning. I recognize that I stand between you and lunch, so I hope this will be really riveting.

[Laughter]

And it's on a topic that, as Brian said, we're shifting to health. But as he mentioned, health is so crucial to employment.

So I hope you will enjoy this presentation. Before I start, I wanted to acknowledge that what I'll be doing to begin with in summarizing the secondary data analysis projects is summarizing broadly 10 separate projects, or 10 separate research questions asked out of the MEPS data. None of these were included in those that Monica just talked about, as she documented there were a lot of gaps. The systematic reviews preceded the secondary data analysis. The ones that I will talk about are not reflected in that data. They were intended to fill some of the gaps she talked about.

I also wanted to mention in case you didn't get one, this presentation is available at thumb drive, on the front table. There are two, one with the employment stuff. The second that is for the stuff we're talking about, the health disparity stuff.

As we mentioned, all of the studies I'm talking about used full data from the medical expenditures panel survey, or MEPS. This is a nationally representative sample of community-dwelling US citizens. Our work focused, the work of the DRIP focused on the working age of the population. Our analyses included descriptives, C-i-square and involved tests.

As Monica mentioned, we had two separate data sets that were created. The first one covered the years 2002-2008. It used the hearing impairment group as an referent group. Did not include a no disability group.

The second included data from the years 2004-2010. So that is more current data, and it uses the no disability group as the referent group. Also on the thumb drive is a listing of the bibliography for all of the articles I'm talking about today, broadly, not talking about a lot of specifics from those articles.

You will see through these analyses I will discuss that in some cases we are comparing people with any limitation to people with no limitations to broadly people with disabilities to without disabilities.

In other cases we talked about subsets, where we classified the population into one of six mutually exclusive disability groups. These included cognitive limitations, physical limitations, hearing impairments, visual impairments, or multiple limitations. So any two of the other one, two or more of the other ones.

Again, compared those to people with no limitations.

We know experientially and conceptually the population of people with disabilities is not a homogenous group. Instead, there are important differences that vary by disability group, including healthcare needs, communication styles, preferred learning styles and levels of need for support.

In many ways, we've organized our healthcare and public health policy and practices in this way. According to disability type. But while we know through experiences that these differences exist, there haven't been any studies to determine whether there's statistical justification for doing so to support the need to conduct our research according to disability subgroup.

So we did that. That was one of the 10. And this slide very briefly summarizes those findings. I could spend the whole time talking about just that one paper. Briefly speaking, we found that the disability subgroups should be modeled separately. That means we should consider disability -- we should consider groups of disability in isolation from each other. Also, we found that it's not best to estimate any of the disability subgroups together in a single regression, meaning we should -- we have those five groups, five mutually exclusive groups, and none of those should be combined together. Each of them is important in its own right and has unique differences. This was true for the 10 health outcomes we investigated.

The secondary research of the DRIP covered several outcomes. These included health, which includes self-reported physical and mental health, as well as chronic conditions, including multiple chronic conditions. Also included access to healthcare, including access to a usual source of care, whether or not the person had to delay or not receive care that was necessary, and health insurance status. And also clinical preventive services, including dental care, flu shot, and breast and cervical cancer screenings.

When we looked at the health outcomes, we found that for self-reported physical and mental health and chronic conditions, including multiple chronic conditions, that people with disabilities experienced poorer outcomes in general than the general population when compared to the general population.

And, in addition to that, not just comparing them to people without disabilities, but when we compared the subgroups each of the disability subgroups experiences these outcomes differentially. I will talk about those specifics in just a second.

Looking specifically at physical health and there's a typo on this slide. This should just reference the horner Johnson 2013 article, not the others, those with hearing impairments and with vision impairments were least likely to rate their health as fair or poor. And those with multiple impairments were most likely to rate their health as fair or poor, with 55% of people with multiple impairments rating their health as fair or poor. So quite a substantial number.

I'll come back to this slide in a minute, too. But for now, moving on to the self-reported mental health, similar to before, those with hearing or vision impairments had the smallest number who reported their mental health as fair or poor at 5%, and 6% respectively. While those were cognitive limitations or multiple impairments had the greatest number who reported mental health as fair or poor, with 39% and 32% respectively.

As I mentioned, we also looked at chronic conditions. These included, which these are the priority conditions within MEPS, these include asthma, cardiovascular disease, COPD, diabetes, high blood pressure and stroke.

The research of this grant examined each of these conditions individually, but we also, as I mentioned, investigated it collectively as multiple conic conditions too, because we -- chronic conditions too, because we know that increases the likelihood for disparities and increases need as well.

Multiple chronic conditions was defined as a person who reported having two or more of these conditions.

This slide shows that all of the groups, all of the disability groups experienced multiple chronic conditions at higher prevalence than the no disability group. All the way on the right, the multiple, those with multiple impairments had the greatest proportion with multiple chronic conditions at 61%.

If you remember from earlier, I said I would come back to this, the prevalence of reporting fair or poor physical health, although the bars are in a different order, those with multiple impairments or physical or cognitive limitations were most likely to report physical health as fair or poor. So if you take these together that those groups who report fair or poor health, physical health, are the same ones who are most likely to have multiple chronic conditions, it explains -- it makes sense that we can see that people who have more chronic conditions are more likely to report health as fair or poor.

This highlights the importance of disentangling the temporal nature of the relationship between disparity and health conditions. I will talk about that in a minute in the policy discussion.

As one example of a specific chronic condition, we examined asthma among those with physical disabilities. In this research, we found that those with physical disabilities were more likely to have asthma than those without disabilities, but they did not experience disparities in the quality of care, utilization or cost associated with it.

At the same time, however, people with disabilities were less likely to have their asthma well controlled. We believe this suggests that people with physical disabilities are likely receiving sub-optimal care in some way, and that the implication is that we need future research to examine the efficacy of asthma-related care, specifically for people with physical disabilities. And for this research to examine whether people with disabilities with asthma have sufficient access to appropriate preventive care and the medications they need to manage it.

When we looked at access to care, overall we found again that people with disabilities have differential care compared to the general population, this is in relationship to the usual source of care, health insurance and delaying or not receiving care.

Again, there are differences among the disability subgroups as well in each of these outcomes.

The differences in the disability subgroups are explained in part by variation in the complexity of the health profile and the healthcare needs, as well as sociodemographic and health factors. I will talk a little more about that in the policy implications as well.

When we looked at usual source of care, those with multiple impairments or physical disabilities or cognitive limitations are most likely to have a usual source of care, all with greater than 80% reporting access to the usual source of care. Those with visual or hearing impairments were more similar to those with no disability, with approximately 70% reporting having a usual source of care.

Also not shown here is that the research demonstrated that among people with disabilities with complex activity limitations, they were more likely to have usual source of care than those without complex activity limitations. So we're seeing some themes here from like what we reported in the self-reported health rating.

In every group but hearing, having a multiple chronic condition was predictive of having a usual source of care. And health insurance, especially public health insurance, was predictive of having a usual source of care. So like we see for the general population, it appears that overall the groups with the most complex health profiles have the greatest odds of having a usual source of care for addressing the needs that they have. So that's a good thing.

But there's still that 20% of people with disabilities that does not have a usual source of care, and as Dodderton cites, the importance of ensuring access to the usual source of care for people in underserved groups who also have disabilities is especially important due to the thinner margin of health they experience, and potentially greater consequences of not receiving timely care. So it's important to keep that in mind as well.

We see similar trends in health insurance status in which those with the most complex health needs are most likely to have health insurance. Those with visual impairments were most likely to be uninsured. Those with no disability or cognitive limitations were least likely to be insured.

However, this trend does not continue through for the delayed and not receiving care. All disability groups were more likely to delay or not -- report delay or not receiving necessary care than the general population. But people with multiple impairments, again, the tall bar at 45%, were by far the most likely to have delayed or not received necessary care.

Similarly, when we looked at clinical preventive services, overall, people with disabilities compared to those with no disability are less likely to receive recommended clinical preventive services and screenings. And this varies by disability subgroup.

And receipt of these also differs by sociodemographic and health factors.

For example, with receipt of mammogram in the last two years, neither people with nor people without disabilities have met the healthy people 2020 target, but people with disabilities have far to go than those without disabilities.

Disparities in this particular clinical preventive service are driven by people with cognitive or visual or multiple limitations. But for all people with disabilities the complexity of limitations, again, influenced receipt. So that those with the greatest complexity were the least likely to receive those -- a mammogram in this case.

As another example, 64% of people without disabilities reported having a dental check-up at least yearly, compared to only 50% of people with disabilities. Both groups have met, notably have met the healthy people 2020 goal of 49%. But you can see here when we subdivide it by the disability type, people with cognitive limitations or multiple impairments lag behind the other groups. In fact, three of the five cognitive, visual and multiple, have not reached the target.

For all of the outcomes addressed by the DRIP research, it's important to note, as I said a little bit earlier, the influence of sociodemographic factors. We included in our multivariant analyses the predictors of age, race, ethnicity, marital status, metropolitan statistical area status, region, education and income, as well as health insurance, usual source of care and multiple chronic conditions when those were not the outcomes.

These factors each had differential impact on the disability subgroups that could have important implications for future research in policy. And we can provide further information on the level of -- that level of findings, if you're interested. There was not time to, and you may not be interested in that specificity for this group. If you are interested in that, you can talk to one of us or check the papers listed in the bibliography.

Now I'm changing hats and I'm playing Kim Phillips. We look nothing alike. She would be laughing right now.

[Laughter]

Disability-related health disparities. We know that people with disabilities can enjoy good health. We know that having a disability does not equate with illness. Nonetheless, compared to those without disabilities, of people without disabilities, people with disabilities experience health disparities that are related to access to healthcare or physical accessibility, meaning the ability to get inside a facility, to be weighed, to transfer to an exam table, to fit into a mammogram machine and things like that.

There are also disparities in receipt of care, adhering to the recommended levels of clinical preventive services and screenings, managing chronic conditions with provider oversight and things like that.

Disparities also exist in quality of care or the opportunity to experience care without discrimination from knowledgeable providers who offer alternate forms and styles of communication, who interact respectfully and free of discrimination and stigma.

Then we also see disparities in health outcomes with higher prevalences for specific chronic conditions, as well as multiple chronic conditions, obesity and poor physical or mental health.

To learn more about the specific nature and contribution of these health disparities, and to work to reduce them, we need to continue to improve surveillance and monitoring. Brian talked a little bit about that. Basically, we need to continue to follow these populations in our research and practice and public health and health policy.

The research we discussed today has clearly demonstrated the importance of recognizing people with disabilities as very heterogeneous group. I will say more about the implications of that in a moment.

The ability to monitor and conduct surveillance or continue to follow the population for research, for different types of disabilities, can be improved as more data sources and administrative programs begin to identify people with disabilities and specific subgroups.

Amy and Brian talked a little bit about that already, and we still have farther to go. So the community, the CPS and the BURFAs adopted these questions, and other surveys are adopting them as well. And that is really great, because for example it allows us to examine data specifically by disability type.

As I mentioned, we still have a ways to go on that, especially for the intellectual and developmental disability population. Because no surveys currently do an effective job in allowing us to identify people with IBD.

We can also benefit from standardized definitions of disability and disability types. Because this will enable us to more easily compare and contrast the information from different sources, and to create a more comprehensive picture of the nature of disability-related health disparities, as well as the health needs and outcomes of people with disabilities.

Further, more than knows whether a person has a disability and the type of disability they have, we can benefit from knowing the complexity of limitations experienced, as we talked about in some of the research today, because as we discussed, complexity of research is frequently a predictor of health disparities.

As we saw in the research, people with the most complex disabilities and most complex health profiles are more likely to have elevated needs. Lastly, we need to ask questions about the age of onset or acquisition of disability. With currently existing data sources we can't easily tease out causality in cases of chronic disease and disability. To cite one example from the research, consider arthritis. Arthritis may cause mobility limitations in some people, but at the same time it's also true that people with mobility limitations are more likely to develop arthritis due to factors not related directly to their primary disability.

Currently, when the presence of a disability and the presence of arthritis are both indicated in a survey, we can't tell which precedes the other. And establishing this would greatly inform the disease prevention and self-management programs, as just one example.

Back to the disability subgroups for a minute. The research we described here today provides a whole lot of statistical evidence for what has been conceptually inferred, and experientially known for some time, that each subgroup of disability type has unique attributes, unique strengths and unique needs, and so what does that mean? Do we need to think about these groups separately, ensure research considers the groups individually as well as combined in order to look for differences and similarities both within and between groups? Yes.

Should we abandoned our infusion approach to programs and policies? In other words, stop mainstreaming and begin launching separate programs and policies? No.

Here's why: First, mounting separate programs like that and programs and policies is both costly and difficult to sustain. Even more importantly, we still have an obligation, legal and moral, to include people with disabilities to the greatest extent possible. In mainstream public health, mainstream healthcare, public policy and health policy.

We need to use our knowledge of unique needs and circumstances of people with different types of disabilities and different combinations of disability types to inform the mainstream programs and policies to ensure that they are universally accessible to all people. And to supplement this, we can use that knowledge to determine when and how to target smaller group interventions more strategically and effectively when necessary.

To shift gears for a moment, yes, our research demonstrates over and over that disability subtypes have different needs and different available resources. But we also have seen that systems level variables, such as usual source of care and health insurance, are important among most or all of the disability subgroups, depending on the outcome variable and interest.

For example, concerning receipt of clinical preventive services and access to healthcare, having health insurance and a usual source of care are the drivers of disparities that we see for people with disabilities, compared to people without disabilities.

The Affordable Care Act forbids denial of insurance coverage to individuals with pre-existing conditions, and prohibits rescinding coverage after a new condition is acquired. This should mean greater access to affordable health insurance than in the past.

The ACA may improve opportunities for people with disabilities to afford needed care by having no caps on benefits and mandating coverage for preventive care.

Medicaid expansion in some states will also mean more coverage for more people. But we need further research to rely on state-level data or we'll need to take state healthcare policies into account when examining national data sources.

So again, the surveillance piece is going to be really important in order to assess how these changes in healthcare law impact the health of people with disabilities and what they might do to reduce the health disparities.

The ACA also calls for training of healthcare providers on the care of individuals with disabilities, and these trainings must teach providers how to deliver care that is culturally appropriate or knowing something about the disparities or barriers that people with disabilities face.

It must be respectful, using people first language, be free of misconceptions about types of care that are or are not needed. For example, an assuming a woman is not sexually active, therefore not require cervical cancer screening.

They must include how to overcome barriers, communication disabilities, cognitive limitations or low literacy. That is they need to know how to provide alternative formats of communication, interpretation, or translation when it's needed.

Training also needs to cover logistical issues, such as accessible medical equipment, like adjustable exam tables, methods to weigh wheelchair users. How to help people with mobility limitations transfer. And accessibility of healthcare facilities.

And finally, people with disabilities need public education about health and healthcare. One good example is the CDC's right to know campaign, which teaches women with disabilities about the need for breast cancer screening. And another example, or another point is that people with disabilities who are less educated may have greater difficulty understanding and taking advantage of changes to the law under the ACA. So we need targeted outreach and education efforts regarding this topic.

And I don't have that slide.

[Laughter]

I'm happy to take, we're happy to take, questions. Thank you.

>> Hi, I'm David Hart, an advocate representing an organization called VOR for intellectually disabled individuals. If I understand what you presented, my question is individuals with multiple disabilities, multiple diagnoses, are more apt to have health insurance, correct? Or to be insured. Is having the health insurance and I indicator they've actually been seen by a health professional? You said people with health insurance are more apt to have seen health professionals. Is that a hard -- have they gone to doctors' appointments, I guess, to do they just have the health insurance and it's unused?

>> Amanda Reichard: I think it's a couple of things. It's a self-reported survey. It's based on self-report. It's also frequently a proxy, so if someone is answering questions for them, but they're supposed to be a knowledgeable person, they're supposed to be knowledgeable about the healthcare for that person.

So most of the people who have the health insurance are using it. But then as one of the slides shows, they are still more likely to report that they had to delay or not receive necessary care. So they may be getting some of their needs met, but not all of their needs met, but they are using their health insurance. It's just that I think we have a ways to go in improving the quality of the care and making sure that all their needs are met.

>> Hi, this is Nanette from ODEP. I was interested in the role of employment in the outcomes you were talking about. I noticed in the multivariant analysis, employment wasn't one of the variables. We're interested in the bidirectional relationship between employment health and healthcare outcomes.

>> Amanda Reichard: Yeah, we made a decision, there was so much correlation between employment and income and education that we made a decision to exclude employment for that reason.

>> Could you just clarify what you mean by multiple disability? Would that be based on the disability that you track, or could that include other disability, like behavioral health?

>> Amanda Reichard: Yes, unfortunately, there's not a whole lot on the MEPS survey that indicates behavioral health concerns. Ity a weakness of the MEPS -- it's a weakness of the MEPS. So it only includes cognitive limitations, physical limitations, visual or hearing impairments. If you had any two or more of those, that's how we defined multiple limitations. I'm hopeful that maybe someday they'll add in more questions about mental health. Right now, it's not a real strength.

>> Good morning. I'm John Huff from the National Center for Health Statistics. Great presentations from a great team.

I'm proud to be a methods curmudgeon. So I'd like to throw a curveball to these researchers and hopefully spawn discussion on the topic for the rest of the day. That is the theme that I like to carry forward, that is that not all differences are disparities. Respectfully, most of the information both researchers presented today refers to differences or differential experiences. I'd like to hold you to a high standard about using the term "disparity" or to adopt common or standardized definitions of disparity that other investigators and pertinently funding agencies adopted too. In a word or two, the definition consistently focuses on a systematic, negative outcome. A medical outcome. That yields bias counts, unless the systematic differences are counted for.

So I'd like to ask you to please comment on a definition of disparity that you've used or that your team has used. Could you describe the definition of disparity that the Oregon health and science university researchers used? Because apparently, that was also the basis of most of this research in a good way.

And finally, could you comment on just the theme of what would be the threshold, if you will, or the degree of difference that defines a disparity for this purpose? Thanks.

>> Monica McClain: So I can comment just based on coming into this project midstream. The title of this project was healthcare disparities. So I think this project defines the disparities based on the environmental, individual and system level factors. But I do appreciate the fact that a difference doesn't necessarily mean a disparity, and I think we do need to be careful about how we express that relationship.

I think that the -- it's a complex and multifaceted relationship between disabilities and the disparity factors. We're trying to demonstrate where those differences are.

You'll notice that in the slides that showed the directionality of evidence, there was -- we didn't show statistical associations, we just showed direction. So I think I see that as a step in not trying to say that it is significant, but these are where there are differences and these are areas where there may be interventions that could be applied to ameliorate some of those differences.

>> That's well said. Thanks.

>> Debra Brucker: So if we don't have any more questions, we're going to move on to lunch. I do want to encourage you, if you are able to stick around for this afternoon, we have a great session this afternoon with our employment policy measurement Research-to-Policy Roundtable. We'll be discussing implications of the November elections for the employment of persons with disabilities, and also talking about WIA implementation. Vice president Biden's review of job training programs. And update of Section 503 implementation and I'm sure it will be a great session. We will reconvene at 1:30. Thank you.

[Applause]

[Lunch break until 1:30 p.m.]

>> Penny Gould: I just want to encourage everybody, if you are feeling shy, we have so much extra food going on over here. Help yourself. Take second, third lunch. Bring something home for dinner.

[Laughter]

There's a lot there, and it was delicious.

>> Mark Perriello: Good afternoon, everyone. Feel free to talk amongst yourselves for just a few more minutes. We're waiting for some of the speakers to arrive.

So good afternoon, everyone. We're going to get started. Thank you, everyone, for taking part in the second part of our day long discussion for the disability compendium and disability statistics compendium.

This is a really great -- I always love the afternoon, because I feel like we start to get into the heart of the matter and move from a strict discussion on the statistics to a discussion about what people are doing to help drive some really great change for people with disabilities here in the United States.

So as I mentioned this morning, we will be hearing from Ellen Nissenbaum from the Center on Budget and Policy Priorities. Then an amazing panel of really star studded panel of folks from federal agencies who are going to be talking a little about what their agencies are doing, to try to make the world a better place for people with disabilities.

As I said this morning, good statistics drive good policy, and that is what this is about. So take this data, take this research, use it in your own work, and help to drive some systematic change for people with disabilities. If there's one thing, and I will reiterate it from this morning, especially for those joining us over the web who weren't necessarily participating this morning, for those in the room who are just joining us now, think of the thing that you can do, just the one thing you can do differently for people with disabilities in order to create some real and lasting change.

We've been coming here now for six years. We've been looking at numbers that haven't changed a whole lot. Some numbers have gone up a little, some have gone down a little, but overall they haven't moved. There are a lot of great, dedicated people working hard, people with disabilities, people working on behalf of people with disabilities, many of you in this room. We should be able to move these numbers together collectively.

That is what this afternoon is about, and I am going to hand it over now to Lisa Ekman, with the AAPD policy team, to kick off the afternoon. Thank you, Lisa.

>> Lisa Ekman: Thank you, Mark. Good afternoon, everyone. I'm really pleased to just lay a little bit of background for the round table discussion that you're about to hear with, as Mark said, a lot of our federal partners who work really hard to try to assist people with disabilities and improve the employment outcomes for them.

Since we last convened, last year, there have been really exciting developments, both legislatively and administratively that can assist with helping people with disabilities to enter and remain in the workforce. One of those that has to get mentioned is the full implementation of the Affordable Care Act. For the first time, people with disabilities, for example, who want to become entrepreneurs and open their own businesses, can get affordable access to health insurance. We're just starting to see how that might impact the employment situation for individuals with disabilities.

We also have seen the full implementation of the regulations for Section 503 of the Rehabilitation Act governing federal contractors, and for the first time any business that has a federal contract has to have a goal of a hiring of people with disabilities.

We also saw the passage of the workforce innovation and opportunity act, which creates new opportunities and changes the way that the Rehabilitation Services Administration and state vocational rehabilitation agencies can work with people with disabilities, including youth, and will create positive opportunities to work more closely with businesses and require some changes around that. We'll hear also the administration's plans for implementing that at our roundtable this afternoon.

We also have seen a huge and growing interest around looking at how to support workers who have impairments and who have disabilities remain in the workforce. So we may hear a little bit about Social Security's plans for doing some early intervention dem on stranges for how to -- demonstrations for how to provide workers with disabilities services and supports they need.

One thing that we have to keep in mind is that all of this is done in the context of what Congress, what resources Congress gives to the administration and to the agencies to implement these new programs and policies. As we're entering the new Congress, we're going to face a very different Congress than we did over the past couple of years. So that will have an impact on the administration's plans and their ability as they move forward with these new laws and new opportunities.

I'm very pleased that we have Ellen Nissenbaum from the Center on Budget and Policy Priorities here to talk about what that looks like in the new Congress. Just to give a brief introduction for Ellen, Ellen is the Senior Vice President for Government Affairs for the Center on Budget and Policy Priorities, and for those who might not know, the center is one of the nation's premier policy organizations working at the federal and state levels on fiscal policy and public programs that affect low and moderate income families and individuals.

Ellen directs the center's work with federal policymakers and with other national, state, and local organizations on a broad range of policy issues. These include federal budget and tax issues, federal policies concerning Medicaid, and healthcare, federal nutrition programs, federal and other critical policies.

She's regarded as one of the leading legislative directors among nonprofit organizations in Washington, and frequently is asked to provide support to a number of organizations and coalitions by providing policy assistance, strategic guidens an and communications planning for the legislative activities.

We're very fortunate to have her here today to talk about what we can expect in the new Congress as a backdrop for our roundtable in terms of implementing policies for people with disabilities. Please join me in welcoming Ellen.

[Applause]

>> Ellen Nissenbaum: Good afternoon. Nice to see everybody. I'm a little worried that Henry asked me he to come after lunch. You're a little tired, you need something upbeat and cheerful. It's not going to be what this is all about. Hopefully, you will hang in there with me.

I'm really pleased to be here. I can't stress how your organization is and the voices that you raise on these very critical issues, and we are very, very fortunate to have partnered with Henry and Lisa.

We've done a lot of work with the community on a range of issues. Those who don't know, the center is nonprofit, nonpartisan public policy group, affecting low and moderate income Americans. We've also built a network of what I shorthand called little mini centers on budget in about 40 states around the country that do similar work on state fiscal policy, state budget choices, and state healthcare and other issues. We'd be happy to connect you with our network if they're in some of those states.

One of the areas in addition to the budget work we do is a tremendous amount of work on Social Security, particularly on disability insurance. We're very fortunate to have two of the nation's experts on DI, and they've written papers and blogs on the issue, and much of our work is cranking up as we'll talk about.

Henry asked that I start, I have to talk fast with a very limited amount of time allotted, to give you a little sense of the change in Congress. I'm going to do that super fast, then there are a couple of PowerPoints. I understand you have access to this, so just a couple I want to highlight. Particularly what I think may be the two single greatest threats from the macro intersection of fiscal, health and policy on disabilities, what are the two biggest threats next year.

Just to start quickly on Congress, obviously we have a bit of a sea change in Washington that will present us a new array of challenges. I would still argue also presenting us with some opportunities if we are very strategic in how we approach those. Clearly, we have for the first time in a long time Congress controlled by one party, the White House controlled by another. I'm a little nervous, I do a lot of presentations to groups and a lot of groups said, well, nothing will get done. It will be massive gridlock. I think that will be an incredibly dangerous assumption, because I think a number of things will get done. There will be some bipartisan agreements, and there will need to be as we'll talk about in a moment an effort to make sure that there are not bipartisan agreements on what could be really radically restructuring of Medicaid and very harmful changes on DI as well.

The house hasn't really changed much. They've picked up more seats, so there's not a lot of news to say there, except I would tell you without getting into the details we have fought in the last two weeks on a tax bill moving through that is primarily about tax breaks for corporations, but it was leaving behind tax breaks for low and moderate income families and the nature of the earned income credit and child tax credit, and a very bad bipartisan bill emerged. The administration issued a veto threat. That legislation is dead because it became clear that the House could sustain a veto. In many ways, the House becomes more important, even though the ratios changed, in the sense that if there are very bad proposals, they make it through the Senate, the question is whether there may be numerous opportunities where what our most important job is to sustain a veto and make sure there will be vetos of particularly harmful changes.

The Senate is really the game changer. In many ways, it's almost a virtual flip. We had 55 Democrats, 45 Republicans with the expected outcome of the Louisiana race, there will be 54 Republicans and 46 Democrats.

There are thee immediate ramifications -- three immediate ramifications or three immediate implications of that change. The first is committees. For the moment I think it's safe to say that you can look at the committees that you have now and flip the numbers. So for example, I think the Finance Committee is something like 11 Democrats and 9 Republicans. At a minimum, that ratio would flip. You can look at other committees and just understand that the numbers are changing. It does mean in some committees that some members are going to lose their seats. So we really won't see this play out for another several weeks, but we will have some champions that come off committees, we will have new champions and new members that need to be educated very much on the issues that you really care about. So that's the first.

The second is that in the Senate it takes 60 votes to do absolutely everything, and anything. So that is both an opportunity and a challenge. The opportunity presents itself for those who will be looking for 60 votes, meaning they will be looking to put together bipartisan agreements, and to that end may be willing to make compromises on legislation that the majority puts forward in order to get 60 votes. If you look at the pool, there is a pool of moderate Democrats and others that may be interested, some have already spoken out about the need to help build bipartisan majorities in the Senate to put together legislation, that's an opportunity in the sense if there's legislation moving forward, it doesn't look like it can be stopped, there may be policymakers who are able to make a significant difference in the shape and contour of the legislation.

I would also note the flip side, that is they need 60. If there are very bad proposals moving on disability insurance, Medicaid, discretionary spending, it is conceivably possible on the Senate to prevent them from getting 60 votes.

So the short list is you're going to spend a lot more time thinking about vetos and whether we can sustain them. We're going to spend time thinking about are there opportunities for constructive bipartisan proposals and how do you help build a bipartisan majority to do that in the Senate. But I would venture to guess we'll spend more time, at least in the center, trying to make sure that they can't pick up six votes if there are very bad proposals moving forward.

The other political context piece of this is if this takes many of us back to 1995 with President Clinton and a Republican controlled Congress, they had to make very important choices about where they worked with the Congress, where they drew the line on vetoes, what they accepted. Many of you may remember that he vetoed the welfare reform bill several times before signing one. How those dynamics shape up will be very important, about where the President draws lines and helps build bipartisan support for a number of things.

So let me quickly go through a couple of things just to give you a sense of some of the biggest policy parameters for next year.

The single most important thing to note is that we will not having had a budget for a couple of years, because there have been -- we are looking at a very major budget fight. In many ways, it represents the biggest threat to healthcare in a very, very long time. Outside of the budget fight we have obviously a real challengen to the DI program.

If you look at this, it tries to put into graphic form that the fundamental nature of the budgets that the conservatives are talking about putting together and have put together in recent years is one that says we're going to balance the budget in 10 years without revenues, without defense cuts and without affecting current retirements.

If you take -- you have to balance over 10 years, you take all those off the table, there is nowhere left to go except two places: Critical entitlements for vulnerable Americans, and appropriated programs. That's the only place left to go. They may do some savings in Medicaid -- in Medicare, but with a lot of members, majority up for election in 2016, I wouldn't venture to think they'll go down that road.

We are particularly concerned that it the single biggest target in the budget plan -- let me just say one thing about the religion et plan. A budget resolution in Congress is simply a fiscal blueprint of their priorities. It's not a law. It doesn't go to the President. What makes the coming year different is that they will use a tool that David stockman developed in the 1980s which does become a law, which many have been through numerous times, called a fancy term reconciliation. All it really means is the budget will set up a process where key committees will be required to make cuts in programs, programs of their choosing, to produce a certain amount of savings, and other committees will be given the opportunity to reduce taxes, probably without paying for them.

We're setting up a budget process that, as it unfolds, does put into place the beginning of development of a law called budget reconciliation that will go to the President for his signatures or veto. And probably one of the single biggest areas we think this he will target is Medicaid.

Many of you have been through the Medicaid block grant fight with us before, though nonof us have been through a threat with the Medicaid expansion to ACA on the table, where many states have taken it, other states, other Republican governors are beginning to look at modified Medicaid expansion. So we're clearly not done.

They're not necessarily going to do a block grant, but will do something on the flipside, a per capita cap. The way the per capita cap works is you can still have more people in a state, a plant closes, a flood, some disaster, an epidemic, if more people in the state become eligible you can serve them. But you get a limited amount of money per person from the federal government. That limited amount doesn't grow with the cost of healthcare.

So think of it as a gradual noose around the neck, where every year the amount of money you get falls lower and lower below the amount that you need to keep pace with basic healthcare costs. Think about the per capita cap not as one cap that may do one for children, one for disabled, one for elderly and one for all other adults.

Well, how do you set a cap now if you think about the fact we don't know what the growth rates are going to be, if you're in a state that hasn't expanded Medicaid but you're thinking about it, that would affect it. Even in the expansion states, many more people are likely to come under the program. We also know we're getting older as a country, but we know that the elderly are getting more elderly, and that becomes a very, very expensive population within Medicaid. So you're playing Russian roulette with the Medicaid program, where you're not converting to a block grant, but converting to something that over time will shift enormous costs to states, and it will come hand in hand with new flexibility for states. They will give the governors the per capita cap. They will say we're putting the cap in place. Over time we'll save money, but don't worry, we're going to give you a lot of flexibility on your program, flexibility in eligibility, flexibility in data cuts.

Over time, there is no way states will be able to avoid making harmful changes that affect beneficiaries and dramatically reducing provider rates.

This is absolutely, they are very public that they're going down this direction. It's probably the single biggest threat in the budget coming forward. It sounds more reasonable than a block grant. It's a little harder to explain. We have begun to develop a bunch of materials, but it is something we're all going to have to work on quite a bit.

I'm going to flip through these quickly. This is to show you on discretionary spending nondefense discretionary spending. We have two kinds of appropriated money, defense and nondefense. This funds everything from NIS to SSA administrative costs, border pole, you name it. We radically cut this side of the pie very deeply over the last several years. In fact, we've cut it twice, 2011 we -- the Congress agreed to take a trillion dollars out of total appropriations in the next 10 years, but they came back and said when there was an effort to have a joint committee or super committee of deficit reduction, when they failed they took that size of the pie for appropriations and whacked it even more.

We've had relief from those cuts for the last two years for budget deal. Those cuts are coming back next year. On the nondefense side we will face a cut of 9 or 10 billion dollars in funding available for those programs, if you measure in inflation adjusted terms, unless we get another budget deal to address the dramatic drop in discretionary spending that is coming forward.

What I really want to mention since I have very, very little time left is the other major threat that we're worried about. The good news is that while everybody knows we have to address the shortfall in the SSDI program, because of the way the budget process is structured they cannot touch Social Security in the budget. They can't cut Social Security in the budget. This budget reconciliation process where you are requiring committees to produce legislation that makes certain savings, they can't touch any part of the Social Security system.

That doesn't mean this doesn't move forward. A number of people have said to us if they do a budget reconciliation bill and slash the heck out of Medicaid and cut other programs, why wouldn't the President veto that? Plus they may put in a tie it or hold hostage increase of the debt ceiling for entitlement cut. There's a lot of talk of a bad budget bill, but it would be vetoed. That is probably right. It will be a very bad bill, and if that etc. The case it will probably be vetoed. That leave a false sense of assurance we can beat that back. Next summer, we will face the debt ceiling needing to be lifted or we default, the sequester will come back in, and we have no idea what the Supreme Court decision is going to look like in June around whether the subsidies are constitutional in states that have not set up exchanges.

There is already growing discussion about a set of critical budget negotiations that would happen next summer where anything and everything could be on the table. The administration's number one priority for next year is to find a way to replace that sequester, to get out from under the additional appropriations cuts. The price of admission to that conversation for conservatives is entitlement cuts and entitlement structural changes.

Medicaid could come up, and in that conversation ACA changes would come up, and DI could come up in that conversation. What I wanted to warn you is that in the past when we've had shortfalls in Social Security retirement DI, we've done a simple reallocation of the payroll. One can note that the amount of the payroll taxes that goes to DI has historically been underfunded. But it is no longer a simple thing to simply reallocate the payroll taxes to address the shortfall, to avoid a 20% cut in all DI benefits. It is very clear now that to avoid the shortfall and have the reallocation, there are very important policymakers who want to hold that hostage to changes in benefits and changes in eligibility in DI. If we do it once, then we are setting a precedents that in future times there will always be a price if we have to address it.

The problem is that there are very few policymakers who really know much about DI, but what they do know is the terrible NPR series, the terrible 60 Minutes show and the terrible series about fraud in Alabama and West Virginia.

The perception of DI on the Hill is beyond horrible. It comes down to four or five major myths that is is out of control, riddled with fraud, easy to get on and no one gets off. I could go on.

In the remaining three minutes, what I left for you in the PowerPoints is just a couple of things quickly. We have a whole set, if you go on the center website, you look under disability or Social Security, we have a chart pack on DI. There's probably 30 slides that go through the myths, the misunderstandings, facts and key points we think are important for the policy and policymakers to know about it.

You can see right here that there are really good answers to the growth. It's the aging of the population, it's the fact that women are much more now a part of the labor force, it's the fact that the retirement age has gone up. All ex politicable factors for the -- explicable factors for the growth, but very few understand.

This blows policymakers away, they're like really? That the growth in DI has peaked off? It's now -- the rate of growth, it doesn't mean the program won't grow at all, but the rate of growth as you can see is now tapering off.

This one we use, we did a lot of briefings this summer on policymakers, and this one they were stunned. They thought everybody got on DI. If you didn't get on the first round, you always got on the second round. When they find out fewer than half of those that apply get on either in the first round or through the appeals process, policymakers are pretty surprised about that. They're, by the way, equally surprised when we show them how incredibly modest DI benefits are. There's very little understanding of the meagerness of the benefit and very little understanding that many of those relying on DI are very low income.

We talk a lot about that group between 50 and 64, that have critical impairments that are not going to be able to go back to work for whom DI is the major source of income, and many policymakers don't know that.

Members like to have it both ways. They like to say, well, there's tremendous fraud, tremendous abuse, why aren't we cracking down on that? Yet, Congress has really failed to maximize their ability to put dollars into the SSA administrative budget that would be for things like CDRs or dealing with the backlog that is there. This gets back to the discretionary spending, if we continue to cut over and over the pot of funding for domestic appropriations, we are in fact making it hard to address some of the issues that we should be addressing in terms of program integrity and administration within DI.

I don't think the DI issue will move quickly, so we have a time table. We'll start with a budget process that will start February to April, and that will really lay out for us the threats on Medicaid, the threats on Medicare, the threats on SNAP or food stamps or other areas. We'll have a dual track process of the committees looking at specific entitlement changes, while other legislation is moving forward.

We don't know whether DI will come up in 2015 or 2016, but we assume that there will be action and we need to be ready.

So much of this will be frankly driven as it sadly is in Washington. Much of these policy debates will really be driven by the budget. The budget tends to drive policy, even though it isn't necessarily driving it in good ways.

I think thinking about how the budget process sets the table, what are the signs we get from that, and what are the battles it demands us to enjoin will be very important to go forward.

There's probably a lot more could talk about, but in the very short amount of time let me leave it at that. I don't know if there's time for -- if there's questions or anything I wasn't clear on.

>> Henry Claypool: We could take a couple of questions. If there are any.

>> Ellen Nissenbaum: I know it's overwhelming.

>> Henry Claypool: I don't see anyone. Ellen, you've given us an awful lot to think about here. Thank you. Again, the slides that Ellen has presented are in your USB drives, and you will be able to reference that material.

>> Ellen Nissenbaum: I think I put the website on there. So you can access the chart pack. We'll continue to do this. We've done tons of blogs on DI. There's everything from introduction to the budget process, if helpful. We have a brand-new paper you guys got before anybody else, which is a paper today that addresses a very, very damning myth being used that a reallocation of the payroll tax robs seniors on the retirement side of the program. So there's a new paper I think we either gave you the link or you can find it on the website that explains why that is misleading and overblown attack on what we need to do for DI.

>> Henry Claypool: Jennifer?

>> I know the CBO only scores things that are real. I'm wondering if you take a look at anticipating some budget changes. So for example, with WIOA we could potentially see a lot more investment in transition from school to work, where Mathematica studies show there's such promise in terms of better outcomes. So that potentially could save a lot of money from DI benefits or other kinds of entitlement programs. I wonder if you have looked at scoring what kinds of cost savings could be achieved through further investments in transition programs, for example, and pre-employment programs for youth transitioning.

>> Ellen Nissenbaum: We have a number of people working at the center. It's hard to do. Secondly, CBO does factor, they will do macroeconomic analysis and factor some of those things in, quite often they won't. Because it's not clear or because they don't feel like the projections are accurate or they need more time to see what happens in a program, or because they're just pretty modest and they don't change the large picture.

I would just say we have to be careful what we ask for. One of the single biggest changes that conservatives have indicated they're going to make next year, unfortunately they can make it pretty much unilaterally, they don't even have to pass a law, to require the congressional budget office to use dynamic scoring. This is a little like that on the tax side, and that if you cut taxes it will generate a lot of economic growth, and it will essentially pay for the tax cuts. So people often said to us if you make investments in education or job training, that should increase economic growth, it might reduce the cost of benefits. It actually works both ways. You could have work requirements and very harmful benefit cuts put into a program that could be scored as saving money, and as promoting economic growth and getting more people to work. So this notion about how CBO scores and changes that might be made may really come back to haunt us in very big ways.

The short answer is we don't have the scoring capacity, CBO does some of it but they do it on a pretty cautious and careful way. So it's hard to kind of look at those bills and say you shouldn't even have to pay for it, or our cost of the bill is really less than the official score, because in the long run we net a lot of savings in other areas. It's just a super complicated area, but it's an area about to become much more dangerous.

>> I have a second part, which is for the people developing the onset of a disability, who were older in the workforce, right now if they have healthcare the government is in a position to perhaps impact the kind of advice they might be getting in terms of staying in the workforce or not. A lot of doctors and healthcare professionals say you have chronic pain, here's your meds, go home and collect SSDI.

I'm wondering if there's any movement to encourage physicians and other healthcare professionals to say here's how you change your ergonomics at work, here is the kind of physical therapy you can do to stay in the workforce, whether you've looked at that at all.

>>

>> Ellen Nissenbaum: We have not. That is outside of our area of expertise. I don't know if Henry or Lisa can speak to that, but that's not an area we have done or have the capacity to do.

>> It's very big dollars.

>> Ellen Nissenbaum: It is big dollars. I think at the end of the day, there are going to continue to be things that will be put into place to try to reduce the rate of growth in healthcare. The irony is that much of what they want to doen to the ACA is repealing some of the things that reduce the rate of growth. What I'm really, really worried about, this is where the Medicaid cap comes into place, remember, you're balancing over 10 years, without revenues, without defense, without cutting current retirees, you need big bucks from somewhere else to get there. The other question, if they repeal some of the ACA changes those will drive up the deficit in very big ways, and one of the ways they could pay for that is things like a Medicaid per capita cap, instead of looking at other things like this, where you can find additional savings.

I think it's going to be a mindset on DI that we have to have some savings, just this blind mindset rather than thinking carefully about investments in the program, ways to save money, changes on the issue with work, work pilots, program integrity. I think a lot of that is going to be hard to drive that conversation the right way, if we allow the mindset of all of this stuff to be we need big savings in health and big savings in DI.

>> Henry Claypool: Again, Ellen, thank you. Jennifer, we'll continue this conversation about early intervention, because we're very interested in that. Thank you, Ellen.

[Applause]

Now I'd like to invite members of the administration to come and join our federal panel. If you'll give us a moment, folks will come on up and we'll begin.

As people are taking their seats, I have the distinct pleasure of being able to introduce a number of colleagues that I either worked with in the capacity that I held prior to joining AAPD and in a position at HHS or those I'm getting to know even more as I am now in the nonprofit world working really on important issues related to people with disabilities. So I don't have extensive bios to share with you on our panelists, but I just wanted to quickly go through and introduce to you who they are.

We have with us today to my left Sharon Lewis, the carrier of two titles. She is the Principal Deputy Administrator at the Administration for Community Living. And the senior advisor to secretary for disability policy.

She and I go way back and she's holding the position that --

>> Sharon Lewis: It's the ex-Henry position.

[Laughter]

Formerly known as Henry Claypool.

[Laughter]

>> Henry Claypool: The important work going on at HHS is really being led by Sharon around disability issues. She's a critical partner in the department and she's been very gracious in making herself available to work with us today.

We're joined by John Tschida, the director at NIDRR. He is in two worlds as we speak. On paper, I believe he's over at HHS right now, but in reality he is working at the Department of Education and they're in the process of transitioning to HHS.

John comes to us from Minnesota. He has a very rich background in disability and health issues. And so I think we were all excited to see him named as the director ever NIDRR. He has research background that extends to some previous work that he did while in DC at the national rehabilitation hospital. So he's familiar with NIDRR from a couple of perspectives. One being a grantee.

Then of course, we're joined by Janet LaBreck, the commissioner at the rehab services administration. She's in an incredibly important role leading our VR system at a time when they have tree mend opportunity before them -- tremendous opportunity before them. WIOA is on their minds, I'm sure, every moment of every day. Janet comes to us for those who don't know from Massachusetts where she has a long and distinguished career in service to people with disabilities at the state level, and it's really to our benefit to have you now at this point in time leading the rehab services administration, helping our state VR partners rally to some of the important opportunities that WIOA presents.

I won't say finally, but -- oh, excuse me, I've got Dylan Orr, who is with us from the Department of Labor. Those that don't have the pleasure of knowing Dylan, he's in a really critical role. He serves as Chief of Staff to Assistant Secretary Kathy Martinez.

What I really like about Dylan's role is that he is the connector, and he's instrumental in making sure that the ODEP agenda is touching all of the other agencies in the department.

I know that the secretary's front office relies heavily on him and making sure that ODEP is included and part of all the activities that are going on at Labor, making sure that disabilities are part of that work. We're really pleased to have him.

And Robert, thank you for joining us today. You're serving as the deputy associate -- excuse me, deputy associate commissioner. I can't believe I messed it up. Used to work in SSA. I used to work in part of SSA that has been brought together with a shop that used to be called OPDR, forgive me the acronym, I'll leave it there. But for those that aren't familiarity with the Office of Employment Support Programs, it has been brought together with the research arm. So now through this one office they're both running the program, the ticket program primarily, and conducting a very rich research portfolio.

We've been over knocking on their door recently about an idea we had for some interesting things that might happen with state VR, and so we've really enjoyed working with you and David Bieber and we look forward to hearing today from all of our panelists.

We'd like to start with really a quick five to 10-minute overview of your agency's priorities. I've given some background on the -- to our attendees about the administration's kind of major policy priorities or initiatives, being the Vice President's job training review, which wasn't disability specific but it's a great training to think about.

We've heard about 503, federal contractors hiring people with disabilities. And of course the workforce investment and opportunity act is a major piece of legislation that had very significant disability implications. So I'd like to have each of the panelists, they don't have to address those issues specifically, but just for the audience knowing those are a backdrop for the types of comments that you'll hear coming out of our panelists. With that I'll get out of the way and turn it over to Sharon.

>> Sharon Lewis: Thank you, Henry. Thank you, and it's great to be back, and a little sobering after Ellen's presentation there.

From HHS's perspective, obviously our continued chief priority is the implementation of the Affordable Care Act, and given the context of the conversation today I'm not going to delve into far into that in terms of the implications here. We're all waiting with bated breath in terms of what happens with the Supreme Court decision and continuing to work with states on expansion.

The election brings both opportunities and challenges in terms of Medicaid expansion, and continuing to work with the states on the implementation of the provisions under the Affordable Care Act that are very important and near and dear to people with disabilities, including new authorities for long-term services and supports and ensuring states are maximizing those opportunities, working on the implementation of the home and community-based services regulation and encouraging states to provide technical assistance, to stand up transition planning for service systems so that the regulatory changes that were made earlier this year do really encourage and promote competitive integrated employment for recipients of Medicaid services who are, in particular, receiving long-term services and supports that are under the authorities affected by that regulation.

We're in the process right now of working with the states in getting all those transition plans and encouraging states to think about what needs to happen so that employment really, truly is the first and primary option for folks in terms of the home and community-based services.

Related to that at HHS we're also engaged in a conversation about quality. For those who were here last year, we talked a little about this, but one of the important pieces that doesn't hit most people's radar screens, because it's not very interesting, and it's not front page news fodder, but is that the Affordable Care Act for the first time really established a national quality strategy as it relates to the provision of federally funded health services across the country.

One missing piece in the overall quality outlook is really related to long-term services and supports. We are way behind in terms of the establishment of an evidence base that will allow us as we're expanding Medicaid resources to really look at what does it mean to provide quality services in the home and community-based services setting. We've really developed that system on the back of the civil rights and social model, with health-related dollars, and we really need to get caught up in terms of what are the metrics and how are we going to determine that those investments make sense.

So earlier, about two months ago, back at the end of September, beginning of October, we announced that the Administration for Community Living and CMS are partnering with the National Quality Forum to begin to do the analysis and it's a long process, but to begin to develop and look at what does a framework and a structure for quality measurement in home and community-based services writ large look like. So that continues to be a high priority.

If we don't do that work as managed care entities move further and further into the Medicaid space, they're asking the question what are we buying in a capitated rate system when we're talking about long-term services and supports? What are we buying? When we say we're buying a diabetes intervention, we know what we're buying. When we're buying inclusion supports or employment supports or home care, what does quality look like in that space beyond basic medical clinical measures?

So that's a very high priority.

Certainly, the implementation of WIOA is important. We at the Administration for Community Living are working on welcoming our colleagues from NADLR, we call the institute, because we don't like the long, new acronym. Not that we don't like the content, but it's too hard to say. As well as the independent living programs and the instant technology programs. We are in the midst of that and spending a lot of quality time with colleagues at the Department of Education. For any of you who have not spent time in state or federal government, I can assure you that moving a program from one branch of the government to the other is not something that I would wish on anyone.

[Laughter]

In terms of process. It is everything from crosswalking administrative legislation and determining what the impact of every little piece of what the difference is in how HHS administers programs, to what the Department of Ed is administering, to how are we going to pay for physically moving people when none of that was contemplated by Congress.

So we're in the process of navigating all of that and we're hopeful that we will get through it soon, but we don't have a date. Which is always top of mind for lots of folks. In the meantime, HHS is administering the policy aspects of the programs.

The law did go into effect upon signing, which meant that instantly those programs were the purview of HHS, which then meant we delegated back the day-to-day authorities to the Department of Education, but in terms of policy decisions they are being made at HHS in collaboration with the Department of Education and we're moving forward on that.

The last thing I wanted to mention briefly, is in terms of WIOA there are a lot of opportunities in terms of some things Jennifer mentioned related to transition age youth. I know my colleagues will talk about some of the initiatives at Ed and Labor. At HHS we're a little less central to some of the WIOA, other than program transfers, but we are certainly working very, very closely and collaboratively with our colleagues at Ed and Labor, both in terms of the implications related to the transition age youth, the Section 511 I think we're still grappling with how we're going to manage and navigate that which is the provision in the law that requires youth age -- individuals who are seeking to participate in subminimum wage 14(c) certificates to go through a process and have the opportunity to look at competitive integrated employment before they engage in those activities. As well as there will be a federal advisory committee we're in the process of working with DOL to stand up to look at the 14(c) certificate issue and really think about policy recommendations for the administration and for the Hill. I don't know where we go with that.

So a lot going on, and I think that Janet and Dylan and I are spending lots of quality time together.

[Laughter]

In many rooms discussing the WIOA implementation.

With that, I will pass it on.

>> John Tschida: Thank you, Sharon. Is this working? Great. Well, thanks to the organizers for the production of this compendium, which from the outside is a document I used often in my previous post. In my previous post, which was a large vertically integrated health system in Minnesota I spent the final year there working on a merger of a smaller organization I used to be a part of in the research and policy capacity, which was a $50 million organization integrating that into $3.2 billion vertically integrated health system.

Little did I know I wound find myself doing almost the same thing in my current capacity and was among those that didn't think this Congress would give this President the jobs bill in an election year, but I've been wrong before with my political radar, I'm sure I will be again.

I can attest that WIOA has had a profound effect on at least one individual with a disability. That would be me.

[Laughter]

I'm guessing Janet might say the same thing.

[Laughter]

That is something that I've been living and breathing since late July. In terms of priorities for our organization, I'll talk a little about our funding priorities in a little bit. Number one, organizational priority is the successful operation of the institute into the Administration on Community Living.

These folks are not strangers to us. We are working on multiple projects right now, have been for a number of years. A couple are funded projects in our RRTC based out of the University of California San Francisco on community living. A big chunk of that is related to the quality agenda that Sharon mentioned and we welcomed the input and content expertise from colleagues at ACL with the family support priority that they helped us write and are also helping us to manage. I think that project based out of the University of Illinois, I believe, is also just begun, but working very well.

I think there's a very strong philosophical alignment between our two organizations. Our roots are in the Rehabilitation Act, as many of you know and all that that implies in terms of integration and full participation for individuals with disabilities.

Our mission has not changed, as we move toward and join forces with ACL. We're still in the business of promoting, producing, rather, new knowledge and promoting its effective use. Our mission has both an individual component to it as well as societal or systemic component to it, as many of you probably know. The second part of that mission is obtaining society's capacity to ensure the full participation of individuals with disabilities. That also hasn't changed. Historically, we've done some very targeted, small investments where there needed to be disability competency and expertise at the table. I think the accessibility of the worldwide web is probably a great example of that. We will continue to look for examples to do that in the future, really asking that but for NIDRR question. Who's not at the table representing disability? Where can we invest in many cases small amounts of money to be leveraged into larger opportunities for the agencies? Driverless vehicles is an example, where we're partnering with WNDOT. You might think that is crazy, but not that far off and opportunities for individuals with disability is profound.

We have investments in cloud computing and personal accessibility. Being being able to log in anywhere and have your adaptations and accessibility needs delivered to you from the cloud, whether a library kiosk or a person with a computer is also example of some of the things that we will invest in, continue to invest in.

It's a bittersweet transition. We've developed very strong partnerships with our RSA colleagues over the last number of years. We will remain in the employment funding business. We have more than 70 projects we are funding related to employment in one way or another. Think of the population or subpopulation, yes, transition age youth is one where we invested, will continue to invest in things like return on investment or VR programs. We have a report that's going to be coming out in short order that is related to that. In partnerships with our RSA colleagues.

Some of those joint funded projects will continue in the same way that we are jointly managing some of the projects I mentioned with ACL, and I expect our relationship with the RSA staff will continue as well.

So very briefly, our immediate priorities, beginning to publish our funding priorities for FY 15 or FY 15 spending plan has been approved. You will see the details of that in very near future. You will not see a radical departure from what we funded in the past, our three areas. You will continue to see funded community living, employment and health and function. If you look at our long-range plan, it calls for balance across populations and across those domains. So we will continue to be consistent in that way as well.

Our priorities will be published, not from the Department of Education, but under the Administration on Community Living. In many ways we are thankful for that from a regulatory standpoint and the level of burden that is often required in getting community education clearing process. Not that we don't love our friends at education, we just like them to touch our pieces of paper many fewer times.

[Laughter]

Before they go out the door. We are excited about that. Sharon mentioned some of the administrative challenges with the move to ACL. Making sure that our grant management system transfers successfully and all the archival data that goes with that. We want this to be a seamless transition for our grantees and our multiple stakeholders. The implementation of our Rehabilitation Research Advisory Council is something I'm very excited about, to help build a culture of research, both within ACL and across the Department of Health and Human Services. ACL is a very strong organization with the program policy and advocacy, they often serve as the moral conscience of HHS, which I think is fantastic and we're excited about that.

Historically, they haven't had research capacity. They do have a strong valuation and component, so we're looking forward to blending that program and policy capacity with our research competency and capacity and looking at building some structure and expertise around that, those areas.

I think just wanting to be responsive to our multiple stakeholders, and we can do a better job of that. We've got a number of phone calls upcoming from stakeholders that Kathy greenland, the administrator and I will be doing. Much hike this to get the word -- like this, to get the word out. Where are we, what is the transition looking like, what are our goals for the future.

I'm looking forward to those conversations and continued contact with our multiple constituencies. I will turn it over to Janet.

>> Janet LaBreck: Thank you, John. Thank you, Henry also for the invitation. I'm happy to be here sharing information on WIOA and what RSA is actually doing for priorities and how we're working in partnership with both our federal colleagues as well as some of our external partners.

I think I will start first with WIOA, because obviously that is our first priority. As you are aware that when WIOA was signed into effect, for our agency and our program, the national VR program, we were signed into effect it immediately. Which had significant implications for our ability to begin working on all of the issues that surrounded WIOA. We first needed a very strong understanding of what we were being asked to do by Congress and being able to interpret it and understand as best we could the intent of Congress in terms of what their expectations were. Along with working alongside with our colleagues at Department of Labor and all the other core partners who are critical to the inception of WIOA when it was signed into effect.

As you can imagine, trying to get federal partners to all work together in this kind of a system, in a process where some of us have immediate implementation and others are staggered and there are different systems that are in every federal agency, I thought things were complex when I came from the state agencies, and I really mean that sincerely. I had no way of knowing how complex and all of the implications that having a major piece of legislation that is so sweeping, not only for the VR program, probably impacting the VR program more than any other program right now, but the incredible complexities, incredible level of expertise and issues and implications that need to be taken into consideration are enormous and are time-consuming.

So right now, our primary priority has been to work with all of our core partners who are at the table under WIOA and having a full understanding and appreciation of the direction that we need to take and particularly when you take into consideration those specific time frames that we've been given to work in. So it has been an incredible learning experience for us so far in trying to understand each other's programs and the limitations and expectations and working very hard and very closely also with our four partners as well as with our stakeholders in the community, all who have a significant investment in making sure that, first of all, we're doing what Congress is asking us to do, but in addition to that when I came into this position I thought I was coming in to take over a program that really would help with bringing in partnerships, which has always been my very strong emphasis and very strong interest, in working with partners, in developing those core partnerships and looking at performance and accountability, which certainly WIOA is now giving us that opportunity to do. I just never thought I'd be doing it at such a fast pace and immediate sense of timing here as a result of WIOA going into impact.

Also, another important priority for us as well and it actually happened, Henry mentioned earlier, alongside of WIOA, which was very important timing, is the President's job training memorandum and Executive Order. It was very interesting, because I thought that that timing of that piece of legislation, not necessarily legislation that will be regulated on, but memorandum, really does speak to some of the issues that real do truly impact the foundation of the VR program, in that our nation has a huge, huge responsibility in the general population as well as in the disability community to ensure that these individuals are prepared for the work that is going to be necessary and the skill sets that are critical for employment in the 21st century.

We are not there as a nation. We are not there as a disability community. And we really need to have a strong emphasis and focus both on those partnerships with our federal core partners as well as with the business community. And that business engagement and those partnerships and relationships that the VR program has historically had for a very long time but doesn't really get the deserved, I think, press or media or coverage that the program has actually had historically.

I think we are dealing with a couple of different issues that we are going to be emphasizing and focusing on as we work on developing those partnerships, and as we work on implementing WIOA both in a regulatory sense as well as working with our core partners this this process, moving forward through the end of this administration and beyond. And I think some of those issues are things like how do we rebrand this program? How do we make sure people know, Congress knows, that stakeholders know, that our core partners know the work that is being done in this country around employment and around the partnerships that are in fact in place, how do we best prepare the state agencies, who are obviously critical grantees in this whole process, who spend an incredible amount of time, energy, resources, building those partnerships, building those relationships both with their stakeholders as well as with business and industry, who without them we wouldn't be where we are today in terms of the outcomes?

Having said that, we also need to look at the best practices in ways that we can move forward these relationships as well as the outcomes, and how do we best ensure that we are positioned in the agencies for better outcomes, quality outcomes that really do leverage the resources of these programs, but most importantly that position individuals with disabilities to be successful and to move forward with continuing to strengthen this VR program beyond just being with the VR community? How do we broaden the scope of these partnerships and these relationships?

We can't do that without the support, the technical assistance, the guidance of both the state agencies, our research partners, the work that John talked about earlier involving NIDRR and our other grantees around the country are critical issues and critical supports in place to ensure that we can, in fact, strengthen this program and leverage it in a way that is going to be result driven, performance focused and outcome driven as far as the programs are concerned.

So these relationships, I'm so happy to hear and work with John, because when John immediately came in under OSERS our first discussions were about how do we continue to grow this relationship and expand on the scope of work that NIDRR is doing, and ensure that the researchers who are in fact working under NIDRR, that they both understand that we all have this relationship and we're all in this boat together, and that in the end all that matters is we're giving the information and the results, and that we're really assisting the agencies in the end to be able to employ strategies and practices that are going to be result driven.

We are also focusing very heavily as a result of the President's job driven training memorandum, in addition to looking at what individuals need as far as skill sets, to prepare themselves for employment in the 21st century. We're looking also at what our counselors need. How do we best have that dialogue with our agencies, with our researchers, with the educational systems for both high-school level as well as college programs and prepare our counselors for this particular field? Because our practice is and skills we all need and we were all educated on are in fact changing. So different skill sets are necessary.

How do we ensure individuals have a foundation that includes issues like financial literacy, helping to understand what it is employers need, what is the landscape looking like? Where are the labor market trends moving towards?

All of these things complement, all of these issues complement WIOA, the job driven training memorandum and really gives us, I think, both a foundation and a critical opportunity to work together with our core partners in understanding how our workforce development system works within our country, how do we best leverage it and support that in a way during the regulatory process that we can in fact give the states the flexibility, the technical assistance and guidance that they will need to move forward as we move forward with this regulatory process.

It is a huge endeavor, but it is one that I am so incredibly committed to in understanding ways we can support this program and move it forward and put it in a position that really does, I think, help leverage both the expertise of all the partners and do, in fact, come together, and how do we utilize the dialogue and discussion around the resources that we are all leveraging. Because I think we all know that we heard today what is happening in Congress and we certainly know that that discussion around the those resources are going to be critical for us to be really looking at other ways, alternative strategies and approaches for braiding and blending those resources that are going to be so critical to moving forward, because we all know that the discussion around those resources is not getting any better, and we shouldn't be expecting either significant or maybe not even small increases in the resources that we have.

So we have to get better with this. We have to get more efficient. The expectations and outcomes, I think, are really going to be another area.

We are changing how we are writing our grants. We are changing how we are expecting our grantees to comply with our grants. We are expecting different outcomes, both not only from the grantee perspective but as well as from the consumer and our stakeholders as well.

This truly will take a well-rounded perspective from all aspects to really think about this program very differently. I know that we have partners at the table prepared to do that, and I just look forward to being able to really partner with everyone and move forward as we journey on now moving forward through this whole regulatory process.

Dylan, I'm going to pass it on to you.

>> Dylan Orr: Thank you, Janet. Thank you to Henry and the organizers. I want to reiterate what a few people said about today and the fact that we're in such a critical time to improve. I'm going to talk specifically about employment for people with disabilities. Having Section 503 on the books, having WIOA on the books, having the Affordable Care Act in place, not to mention there's it a piece of legislation being taken up this week in Congress that impacts people with disabilities as well, the equal act.

I want to start talking a little bit about Section 503 just to make sure everybody's knowing what they should know about that effort and the opportunities that it presents.

As most of you probably know it became effective March 24, 2014, and I just want to put out this statistic because I think it's so key, that DOL estimates that a federal contractors metricals, that federal contractors would hire about 595,000 people with disabilities and more that 205,000 protected veterans, including nearly 85,000 veterans with disabilities.

Obviously, this is going to take all of us, so OFCCP and ODEP then our federal agency partners including those at the table are working hard to make sure that the dream of Section 503 becomes a reality in terms of implementation. I do want to say that in FY 2014 OFCCP saw unprecedented 400% increase in the number of recordkeeping and affirmative action cases resolved under Section 503 and VEVRAA, which is also obviously remarkable.

They're doing a lot of work and we're doing a lot of work to educate employers and the community and federal agencies around what 503 means, getting a lot of questions for technical assistance from employers, of course, about reasonable accommodations, things like disability disclosure, which is very, very key in this day and age, discussion point and research topic I would say.

On that front, I would say that one of DOL's and ODEP's priorities is to support employers when implementing the regs and Executive Order 13548 governing federal agencies. But with the specific emphasis on federal contractors, federal agencies, then states.

Many of you know there's a lot going on at the state level, a lot of momentum calling on the National Governors' Association, priority in terms of employment of people with disabilities at the state level, and a number of now states issuing executive orders following on the Section 503 regs. A number of others are issuing executive orders and other legislation related to employment first efforts, which wasn't to touch on as well.

-- I want to touch on as well.

One of the things ODEP has done is awarded a new cooperative agreement to a new technical center that will focus specifically on federal contractors, as well as federal agencies and states. Leveraging opportunities presented by 503 and other efforts I mentioned.

They are going to be working with USBLN. USBLN, George Washington University's graduate school of education, with the center of study on disability policy, national conference of state legislators in coordination with the National Governors' Association, and the Georgia institute technology center for advanced communication policy and the college of business. There will be a lot going on there.

We're also working and doing research around an employer engagement strategy with the wharton school of business, the next phase of business with the sheller school of business at Georgia Tech. That is exciting work looking at how we should approach and engage employers.

So that's a bit about the employment work. We're also doing a lot of work around the Executive Order as I mentioned before, working closely with partner at EEOC and OPM, especially. And there's a lot more work to be done, but I think we've made a lot of progress on that front.

Another key priority for us is advancing, I'm speaking now with the ODEP hat, advancing employment first and the mandate of Olmstead. So ODEP is doing a lot of work and we're vigorously supporting the national employment first efforts happening across the country to support integrated competitive employment and minimum wage or above for people with disabilities as the first option.

Right now, that work has been working intensely with four different states and one mentor state, Washington, and three protege states, Iowa, Tennessee and Oregon. Then we're also working with now 32 states and the community of practice, and we just had a conference earlier this week with a lot of energy and other states expressing interest in really aligning their policies and funding streams to prioritize competitive integrated employment for people with disabilities, and this obviously also ties into WIOA and the Advisory Committee, which I'll also mention.

Another priority area for us is accessible technology. We've done a lot of work both internally in the federal government with federal partners, as well as externally working with developers and others, and employers, on accessible technology. We know that is key for employment for people with disabilities, talking about things like accessible websites, online application systems, and social media event, which does tie into employment as well as things we're using, our computers, our cell phones, etc., and making sure those things developers understand how meaningful it is and how important it is for all reasons to have that be accessible out of the, box.

I also want to talk about our youth priority a bit. We as part of the job development training initiative we awarded a pathways to careers demonstration project looking at strategies to serve youth and young adults with disabilities in community colleges. Two grandees were awarded funding under that initiative, including a state community college in Knoxville. This builds off the TAA-TCCT grants these folks have previously. They're going to be using the guideposts for success and looking at really what works to help young people with disabilities acquire the skills, degrees and credentials needed for high skills, high wage employments. We're excited about that.

Also looking at apprenticeship, there's a lot of opportunity there, right now, considering the President's focus there and the 100 million just put in place for grant funding to award more workers to participate in the apprenticeship under Department of Labor.

There's a lot to be looked at there in terms of apprenticeships for people with disabilities and how we can make pre-apprenticeship and apprenticeship opportunities more available for people with disabilities.

Continuing our work on individualized learning plans, which are key especially with WIOA's new requirement that at least 20% of local youth formula funds be used for work experiences, because research tells us that's the most important factor in career success for youth with disabilities. They also, ILPs play a critical role for disconnected youth and WIOA has an incredible emphasis there.

We'll continue working on impacting the workforce system, working in collaboration with Department of Education under the WIOA mandates. And we just awarded new grants under the Disability Employment Initiative, which I hope folks know about as well. If you don't, please look it up. It is now operating in 26 states across the country. All of the grantees are required to be employment networks, so we're also obviously working with the Ticket to Work program there, and seeing a lot of success in terms of how many individuals we're serving on SSI and SSDI. We're hoping there will be more success there.

In terms of WIOA, I would be remiss if I didn't mention the Advisory Committee on increasing competitive integrated employment for people with disabilities, which was a WIOA authorized committee. If folks don't know about that, the Federal Register notice went out and closed October 14. I will say that we received over 280 nominations, and really, really stellar candidates across the country.

We're going to look at -- there's also seven federal members, including three from the Department of Labor, plus agency heads or delegates of AIADD, SSS, CMS and RSA. And those announcements and selections will be made over the coming month, hoping to convene the first meeting in early 2015.

As Sharon mentioned, this will have significance, especially in the area of how the section 14(c) certificate program is carried out under the FLSA. We plan on having a very fair and balanced committee, like I said the folks that came in are stellar candidates. We're really hoping that's a great process.

If anybody wants information about that, we've also had a number of webinars, both Department of Labor and Department of Education on WIOA. We have a webpage with our resources on it, if you need to look at that. There are upcoming webinars focused on the nondiscrimination provisions if people are interested. Www.doleta.gov/WIOA to check that out.

I think I will end there. There's a lot going on and a lot of partnership and collaboration between and among our agencies. Even with the headaches it's, I think, going to be positive and it's bringing us together in new ways and innovative ways. I'm excited about that. Anyway, thank you.

>> Robert Pfaff: Good afternoon, everybody. My name is Robert Pfaff. I am from a small agency, small startup agency known as the Social Security Administration.

[Laughter]

Great to be here today. I am representing David Weber, who unfortunately could not make it. I am David's associate deputy commissioner in the obviously of research, demonstration and support. Otherwise known as RDS. I'll try to say everything out first, then give you the acronym.

My responsibility primarily at Social Security, though I did start in the disability side of the organization, and I found many of these presentations fantastic, it's very pertinent to what we do every day, my current assignment for the last year and a half has been to essentially manage the day-to-day operations of the Ticket to Work program. I believe John indicated that we have merged recently, about a year ago, and we are now housed in the research and demonstration part of the organization as well, but my functioning, my staff functioning with the Ticket to Work program.

I'm going to walk you through you a couple of things. We have some things we have already engaged in relative to Section 503 that I want to share with you. Which also have some things we're working on for the future in regards to Section 503 that I think we are excited about and energized about that I want to share with you today.

First of all, to give you a little context in terms of the program itself, the legislative language for the ticket program requires SSA to use program managers to help us run the program or a program manager. We are engaged currently with two contractors who help us run the ticket program. We are engaged with Maximus through the operation support manager contract. They essentially help us handle the day-to-day functions, the operational functions, the ticket assignments, the unassignments and so forth and so on that are the backbone of the organization and the process.

The second contractor that we refer, that we use and I'm going to speak about a little more in length is Booz Allen Hamilton who helps us through the ticket program beneficiary access and service -- I'm sorry, and support services contract. We call this the BASS contract. I want to go back to Maximus briefly, because Maximus' piece is important relative to what's transpired this year. Before I get into that, I want to say that we within the ticket program, and at the executive level throughout the agency, are excited about Section 503 regulations. We look at it as an opportunity to energize the Ticket to Work program. We wanted to take advantage of the new regulations, and we targeted specific activities that were designed to do exactly that.

First of all, through our operations support manager partners, we have administered several training sessions throughout the last year targeted specifically to our employment networks and vocational rehabilitation partners. This has been designed to provide training and an overview and to basically soup to nuts opportunities associated with Section 503. I think they've done an outstanding job. They've been very thorough. We've had a significant amount of participation and we've had multiple sessions. So if one participant has been been able to participate with one session, there have been other opportunities. There are website -- there are links within our websites, and I will talk about the websites in a moment, where you can go in and access this information. It's readily available. We've made it as transparent and accessible as we possibly can.

So that is BASS -- I'm sorry, that is our Maximus folks. Those activities have occurred, they've been recurring throughout the last year. Now I'm going to switch a little bit to our BASS contract and the Booz Allen folks, who are helping us move this initiative to the next step.

The Booz Allen part of this is basically they're our marketing piece. The goal of the BASS contract is basically facilitating beneficiary access to Social Security approved employment service providers, and that's both vocational rehabilitation folks and employment networks.

The website I want to share with you, which I am always engaged in marketing, is our choose work website, that is www.choosework.net. We've actually just relaunched this website. We've made some very nice modifications. It's much, I think much more user-friendly. I encourage you to take a moment when you get back to your work areas and take a look at it, share with your friends.

A lot of valuable information. I know there are varying degrees of familiarity with the ticket program here today, but if you have specific questions about what an employment network is and what services are provided, where can I find one, what is the ticket program, that would be your source of information moving forward.

Understanding that Booz Allen through the vast contract is our facilitator for the marketing piece of what we're trying to do with the ticket program, what we have, what we are working with Booz Allen to develop are -- and what we're hoping to actually -- what we're planning to do for this next year is we want to host four virtual job fairs for Ticket to Work program participants in 2015.

The goal of these virtual job fair events will be to provide an opportunity for our ticket participants and I want to clarify that it would be those participants whose tickets are currently assigned to a service provider, to connect with and possibly be hired by federal contractors and subcontractors who are seeking to comply with their revised Section 503 regulations.

So I'm going to walk you through a little bit of what this would look like.

The employment networks and the vocational rehabilitation agencies participating in the job fairs will be responsible for identifying clients who may be suitable for available positions. They will also inform them of the positions and when the job fairs will occur. They will help them register for the job fair. They will help prepare them for the interview, as well as post-interview processes and assist them to navigate within the job fair environment.

The employment networks and vocational rehabilitation services may also assist their clients in connecting with other service providers. So this won't be merely an issue of the beneficiary and the employer and SSA participating within this realm. We'll also have our work incentives, planning and assistants projects, otherwise known as our WIPAs. They serve as benefits counselors. As well as our protection and advocacy for beneficiaries of Social Security organizations.

We referring to them as our PAABs. All of these organizations and stakeholders will be there participating within this virtual environment and providing, we will clarify which entity provides what services to the beneficiary and all of this is being developed currently.

So let me walk you through where we are right now with this. Currently, there's a lot to this, as you can imagine. We have never done this or engaged in something like this previously, so it's new to us, and I have to credit, we have a tremendous staff at SSA, our contracting service and the folks and our contractors, and we're all working together through this. As you can imagine, there are multiple hurdles. One of which is we're working with Office of General Counsel to address any potential issues relative to the privacy of the job fair participants and to ascertain what steps or legal actions need to be taken to protect individual information.

As our organization reaches resolutions on these organizations, we're also going to work with the Booz Allen team to discuss the job fairs and walk through the conceptual perspective during a future planning and development call.

We have multiple calls that we're working on. We have one that is occurring today where we're going to begin to get feedback from stakeholders and provide information to stakeholders as well as to where we are with this in a similar manner to what I'm sharing with you right now, moving forward.

We're also going to begin to promote the job fairs fairly heavily through various channels, including social media as I indicated previously, through our website, and offer service providers a walk-through of the job fair environment prior to the first job fair.

Our current projected time frame for the first virtual job fair is approximately late February 2015, and we're currently planning quarterly job fairs throughout the next calendar year.

That's all I have to share with you today. So I'm going to keep it short and to the point.

>> Henry Claypool: Thank you to all of the panelists. We're going to open up to questions. As we make the transition, I wanted to pose a question to the panel to see is there a provision of the WIOA that you feel you'd like to draw particular attention to here today? It's an opportunity to maybe highlight something that goes under the radar or reaffirm your commitment to one of the provisions you've already mentioned.

>> Dylan Orr: I'm not going to add anything new, just to say that I would be focusing on the Advisory Committee again. I want to make it clear to folks those committee meetings are open to the public, and we do want public participation and there will also be opportunities for expert testimony. So the folks aren't selected to be on that committee itself, which will be a very small number, there are other opportunities for participation, and we welcome that. So all I'd say.

>> Janet LaBreck: I wanted to add to that as well with regard to WIOA, the RSA in collaboration with OSEP, Office of Special Education under the Department of Education, OSERS, we are partnering together for two endeavors that I think will be critical to supporting the needs of the transition community. That will be to support a joint Technical Assistance Center that will engage both employers as well as families, individuals in partnership together, so that we can address some of those issues.

As you know under WIOA, free employment transition services is critical for the transition age group. So we will be focusing on those areas that will support any issues dealing with transition, as well as other issues that are going to be covered under WIOA.

In addition to that, RSA has recently just changed our very long-term model for technical assistance and continuing education centers, and we now have as a result of the job driven training, we were actually changing that model prior to the job driven training memorandum. When we saw that came out, it reaffirmed for us the need to change our model and our first ever joint Technical Assistance Center that we have under the job driven training memorandum also reflects what is currently involved now under WIOA to emphasize both for the VR agencies as well as for the counselors in providing that technical assistance and guidance that those agencies will need in order to navigate their way through WIOA in looking at the performance as well as outcomes and providing the technical assistance in multiple areas for them.

That grant has been awarded and given to ICI. We're beginning that work as well. Again, we will have other grants that will be coming out. We are looking very, very closely at our previous models and making sure that our grants now align with both job driven training as well as WIOA so that in fact requesting utilization of the resources and making sure our community of practice and our grantees, as well as our consumers are being served by these agencies, that they have an understanding that the resources that we are giving out will in fact reflect both WIOA as well as the job driven training memorandum moving forward.

>> Sharon Lewis: I guess the other provision that we don't talk very much about are some changes that that have occurred under the independent living centers, and a service added to their responsibilities that includes a focus on transition age youth as well as transition out of institutional settings and into the community.

I think the ILs have long done this work, but we're now acknowledging and recognizing that that is a critical component of the work they're doing and should be counted in the metrics and the reimbursement work that they do. So it's not something people have talked a lot about, but I think again it all ties back up into this broader framework around how are we going to do a better job in particular with the transition age youth.

>> John Tschida: Very briefly, I mentioned the rehabilitation research advisory counsel that we had on the books at NIDRR. There were changes made to that council as a result of WIOA to include three additional members. One a small business member, one a provider seat, and the third representation from the independent living community. Looking forward to those additions and getting that group off the ground. I see that as critical, not only to the development of our next strategic plan, but also providing key input on what our priorities should be as we're going forward. Where are we being effective in our research investments? Where are we not so effective? Where should we be investing maybe a little bit more money, especially in knowledge translation to bringing the policies, practices or new technologies to people and into the hands of individuals with disabilities and providers? Again, looking forward to getting that council off the ground.

>> Henry Claypool: Again, thank you, panel. Now hold on, because the entertaining part begins. Hopefully we still have energy in the room. It's time for a few questions. Raise your hand or stand up.

>> My name is Paula Galaday, a federal worker, I represent the IRS here today. I have a couple fess for you. One is -- couple questions for you. One, how are your agencies meeting the goals under 14358, 2% for targeted disabilities and 10% overall?

The other concern that I have, which is tied into that, is when pathways program was initiated, hiring students with disabilities went out the window in the sense of hiring noncompetitively under Schedule A. They're now brought in under schedule D, which is a competitive announcement. That just eradicated so many great possibilities for college level students in the junior year, then going on when they became a senior to get hired into the federal government. I'm wondering how your agencies are handling it, as well as if you see any possibility of that being augmented, pathways being augmented where we can go back to using Schedule A as a noncompetitive hire. Thank you very much.

>> Sharon Lewis: I'm going to defer to my colleagues on the pathways, because I don't know enough to answer on that. I know that overall at HHS we have done reasonably well in terms of the President's goals under the Executive Order. At ACL specifically, we have exceeded those goals, both in terms of targeted disabilities and, more broadly, Schedule A hiring has been a priority for us. And we are pleased to be model leaders on that, I think.

We have, for example, in November convened -- excuse me, in October, convened with the Department of Labor and HHS pulled together some significant event around disability hiring initiatives and the opportunities and really trying to support our colleagues in understanding. Not only the hiring piece, but I think critically, critically is the retention piece. I think one of the challenges that many of us experience in the federal government is the inability to ensure there are adequate resources available for reasonable accommodations because of the budgeting process, not because of a lack of intent but because of the lack of flexibility in administrative dollars and access to administrative dollars, when and how you need them in order to do that. I think there's a lot of interest in how to address the need for centralized reasonable accommodations resources that I think are continuing to occur with our colleagues over at OPM and across several agencies.

It is challenging, and I think we're the first ones to acknowledge it.

The other thing we've done at HHS is we continue to support, I know it's very small, but we continue to support the Project SEARCH model in terms of students with intellectual and developmental disabilities being able to participate in internships at HHS, including through NIH, the Administration for Community Living, and the administration on children and families, as well as really trying to utilize the WRP program and bringing the recent college graduates to go in the direction, instead of pathways, of using the WRP to bring those young adult into the workforce.

>> Dylan Orr: Sharon took the words out of my mouth in terms of plugging workforce recruitment program. I have data here, for 2014, there's 1329 students in that database for the workforce recruitment program. 256 were hired, 19.26%. And 29 federal agencies participated and hired candidates. We want that to be more. The program is also opened up to private companies and they're using the workforce recruitment program as well. We talk about the folks in there, we've got 93 veterans, 125 engineers, 39 MBAs, 90 accountants, 115 healthcare professionals, 47 law students, computer science majors, graduate students, doctoral candidates. We're talking about people from all sorts of interesting and skill sets. So just want to plug that.

I can't speak to the impediments created by the pathways program, but I'm aware.

In terms of the Executive Order, I don't have DOL's numbers, but I again want to say I think there's been a lot of great efforts across the federal government on the end, we have a lot of work to do especially around the targeted disability front. But we've done a lot of work in terms of educating, creating a placement coordinator curriculum, which is key with OPM, EEOC and Department of Labor, updating the ABCs of Schedule A so people understand better what those are, how to use them, because that continues to be an issue. I think folks are working on those issues, it's an ongoing effort, and of course the reasonable accommodations and centralized accommodation fund issue mentioned, as well as accessible technology and 508 are I would say the praises that need the most emphasis and continue to be emfa seemed.

>> Can I ask a quick follow-up? Do you know when the -- I sat on the committee for the SSBCC. I'm well aware of it. Do you know when that is going to be released?

>> Dylan Orr: I don't have a date, but I'm happy to take your card and follow up.

>> Great. Thank you.

>> Henry Claypool: Another question here.

>> Fabulous presentations. This is Jennifer Misrahi from respectability. I really loved your presentation. Thank you. I want to ask about stigma and what each of your agencies is doing to reduce the stigma that people with disabilities are less capable to do a quality job. And I particularly wanted to ask it surrounding 503, because as companies for the first time will develop their own internal scorecards to ensure that they're meeting their 503 requirements their HR directors will, perhaps for the first time, have the ability to create a dashboard of performance metrics of employees with disabilities compared to employees without disabilities.

I have a particular concern that when you have a company like Walgreens and they have proactively put accommodations and thought into hiring people with disabilities, that the outcomes are very, very good, but companies where people have not disclosed their disability and where they have not sought or received necessary accommodations, that there may be a large number of employees who for the first time will self-identify, and when you look at their HR performance records they will not be as good as their non-disabled co-workers. So I wondered if you had thought about that, and whether, for example, NIDRR is doing any studies that will show the difference between proactive, thoughtful inclusion performance metrics, compared to accidental inclusion where there has been a culture of fear where people have not sought the accommodations.

>> Sharon Lewis: I'll take a stab at part of that. So specific to 503, I think we're really working very collaboratively with the Department of Labor who is lead on it, in terms of understanding how we can utilize that opportunity.

I'm not, and I'll defer to both Janet and Dylan on 503 specifically. Certainly at HHS, even internally helping all the procurement officers understand what the implications of 503 are is its own challenge as an entity that is a large purchaser.

In terms of stigma writ large, I think we have a lot of different efforts going. Certainly, we walk our talk. ACL is an entity in which we have people with disabilities in leadership positions, and people with disabilities throughout our entity that I think is critically important, just as in terms of the visibility. But more specifically through the administration on intellectual and developmental disability we are working with eight states in the partnerships and employment grants and have seen some very interesting work coming out of those states in terms of addressing some of the stigma issues and frankly misconceptions.

It's been interesting, in both Wisconsin and California doing some basic community conversations in which the business entities are invited into a conversation with people with disabilities has created opportunities around a lack of understanding that I think, frankly, we often see that the business community just didn't know. Right? It's interesting, the California folks have come back with some very interesting, and again it's not research data at this point, it's anecdote, but some very interesting responses from the business community in terms of we didn't understand that this was a problem. We didn't understand that this is a population that is having difficulties in accessing our employment systems, whether it is those screening tools that many large entities use for entry level jobs. For example, there's a movie theater or retail entity that uses a screening tool that is over 200 questions, that is nearly impossible for a person with a significant disability to get through. I looked at one of them and thought it was impossible for me to get through. That's screening people out.

Being able to bring those very specific and concrete conversations forward, led by people with disabilities I think has been a very effective way for some of those projects to bring that question of stigma to light.

>> Janet LaBreck: If I could add to that, with regard to stigma, the conversation around stigma, particularly where business is concerned, the VR program nationally, particularly at the state levels, state agencies around the country, the importance of having those relationships and those conversations I think are critical around this particular area, because it's many times at that local level where individual agencies, along with their key stakeholders, have the opportunity to really leverage those partnerships and grow those partnerships.

The council on state agencies for vocational rehabilitation has been very much involved, particularly over the last 10 years, in developing the National Employment Team, which is a partnership between vocational rehabilitation nationally as well as with all of our business partners who will come into the net over the past 10 years and have leveraged those partnerships and resources from the VR community.

The stigma issue is really critical to ensuring we continue to have those conversations and grow those partnerships. I've been amazed at the misperceptions and myths, not only about the stigmas around disability, but also just I think in general around federal as well as around state agency programs that are available in the community, and what resources are actually it available to employers in particular.

Many times, particularly when talking about the VR program, free of charge. It is a matter of having that relationship and understanding the connection between the two and VR being able to speak business language and understand what the business needs are, what they're looking for, but also having a need for the business community to really dialogue and understand where the resources are and how can we best position that relationship and that partnership to really provide a service and support, ongoing service and support to those employers.

Where that I think is most effective is when you see those strong relationships over time. It takes time, and that when we have seen those good partnerships that's when you will see that the employers will not only participate, but they will actually increase the number of participants. Most importantly, what comes up of that they talk to their other partners, their business partners, who will share their stories, their share experience.

We recentently had the opportunity to be involved with the White House in coordinating a champions of change event at the White House, where we identified those employers and practices that were being administered in changing how those employers were actively hiring, recruiting, maintaining and promoting individuals with disabilities. Inviting other partners into that process, business partners into those kinds of events, so that they could see that this impact was a viable way and it certainly is a valuable resource and tool to them.

We are also working on another event that will be coming up February 3 at the White House as well that will be an employment summit that we're working on, inviting employers back to that table.

We recently had the event in Rhode Island as a result of the agreement between the state of Rhode Island around Section 511, inviting many core partners to that event for that purpose aroan, addressing the issue of stigma, helping employers understand there are other opportunities and options working with state agencies. They were all present. Individuals with disabilities were present. The best way you can reduce stigma is to engage all partners and making sure that you have successful models there in order to really offset the stigmas and have a system and mechanism for encouraging that kind of relationship and participation.

>> John Tschida: Ed a NIDRR we're funding primary intervention where we're seeing it in the most recent proposals in the peer support context, both related to employment situations and community living situations, diverse populations certainly mental health would probably be top of the line, but also in subpopulations with physical disability, spinal cord in particular.

I also encourage you to go to the information clearinghouse, NARIC, do a search to see what stigmas reveals historically, over the last 29 years of proposals that are all online there in abstract form and all of the major deliverables from those projects as well.

>> Dylan Orr: To add one concrete resource to your answer to the question, which is a great one around disclosure and stigmaened a the connection with 503, we did recently release our new public service announcement at ODEP, that is called who I am, as part of the Campaign for Disability Employment. If you haven't seen it, it is specifically around the issue -- it addresses specifically the issue of disclosure, but -- of disability as being one part of what people bring to the workplace and one part of their identities, and disclosure being such a central question and issue and Section 503 regulation, because you don't know how many people you have unless they disclose and employers keep asking how do we get people to disclose. We say you first need to build an inclusive workplace, and in is how you do it, it starts with these different strategies and practices. That's taking some learning. That people have to realize people aren't going to want to bring or feel comfortable to bring their whole selves to work until the workplace is built for them to bring their whole selves to work to. Anyway, that's -- I do think that that public service announcement is a great one and our last ones have seen a lot of air time, so we're hoping that that one does too.

>> Robert Pfaff: OK, I would just add that with the ticket program, I think we have an opportunity to engage our partners, our employment networks and have vocational rehabilitation service providers in this issue directly.

As I indicated previously, we facilitate ongoing calls and communication with them, and so as I'm thinking about this issue I think one opportunity here is for us to delve a little more into this, because, to be honest with you, I'm sure this is an issue that the service providers are dealing with but is not one that we as the Social Security ticket program have had or engaged directly to date as of yet.

So I think it's a good issue to discuss. I think it's important because obviously there's barriers there associated with that. And we -- everything, a lot of the activities that we're engaged in are really targeted at addressing the barriers to employment for disabled beneficiaries.

I'd be interested in pursuing that.

>> Henry Claypool: Looking for a final question before we --

>> Good afternoon. Thanks, I'm John hough from National Center for Health Statistics. Great panel. Thanks for all your service to our country, in fact. In addition to the importance of the moment that's been described to us by Ellen Nissenbaum and by all of you for reasons related to the election and the new Congress, I'm struck by the importance of the new agency names. I know that sounds pedestrian, but frankly we've turned a corner in the last few years with administrator Lewis' agency and director Tschida's agency coming in, to incorporate the words community living in our agency name, and now apparently independent living, in the complement of an agency.

My question boils down to can you administrators and directors and commissioners help us, we scientists, think about independent living scientifically? Or how do we begin measuring independent living outcomes or if we're in a project officer role, how might we encourage our investigators to think innovatively about community living and independent living as concepts? Thanks.

>> John Tschida: Thanks for letting me go first, Sharon. I think at NIDRR we have 12 mentions of independent living in our enabling statute prior to the passage of the law. Now we have 58. We get it.

[Laughter]

We understand the message. I would say that the community living part of our portfolio has largely been independent living portfolio. We have begun to engage with stakeholders, including the independent living community whose programs are now going to be administered by ACL, to say let's talk about what a research channel looks like from your perspective, let's have you better understand our book of business, here's how we define community living. Let's talk about the language. Language matters. It does. You're absolutely right.

I think there's more similarity than difference there. From a programmatic standpoint, I would say those stakeholders have a clear vision of what their programs should look like at ACL. On a research agenda, much less clear.

Again, going back to our fact committee or our research and advisory council, which the full name is the rehabilitation and independent living research advisory council, which has also been changed. To use that as a forum to help facilitate that conversation, also get input on what an independent living research agenda would look like, how does that differ from some of the community living work that we're currently doing largely around quality and social participation, but getting to assist the independent living centers in bringing rigor to their data collection process, and partner with them on some of these services that they're providing. Now the fifth core service and will there be value in that. Could that be a co-funding opportunity or at least opportunity to begin to look at priority around some policy research.

It's a dialogue I'm willing to have. I agree with you that the language matters. And in fact, we've started the conversation about branding and what that should look like in the name, and strategically how do we want to approach that.

>> It's a new day. A brand of independent living. Thanks.

>> Sharon Lewis: Well, I would echo everything that John said and stepping back a little bit further, when Henry was still with us and Henry and Kathy and I gained the support of secretary Sebelius. We could have called it the agency for people with disabilities and older adults or aging or something like that. We all agreed that the community living was a broader construct.

I think that the interesting opportunity is both within this notion of what does it mean to be supported in independent living goals, but then also for much of our population I think community living is important because we're talking about interdependency, not just independent living, especially as we talk about older adults who are interested in aging in place and may need a different set of structures than are currently available to them. And I would argue for people with intellectual and developmental disabilities it is as much about an interdependency in community living as it is independent living. That's not to say that the independent living philosophy doesn't underpin a lot of the work.

I also think that when we talk about community living, we make clear when we announced the agency and as we moved forward in the work that we see the notion of community living as a holistic approach, and that the challenge that we have right now going back to the quality issues is that when we talk about outcomes, frequently we are limited in our data and research capability to demonstrate and I evidence base in terms approaches that drive toward a quality of life that are not just a social or civil rights model, that are saying if we support people in this way, they're healthier, they're happier, they live longer and their economic outcomes are better. I think if there are folks in the room that are willing and able to pick that piece of the pie up, that is a huge, huge need. Again, especially in the health-related space.

We are talking to our colleagues and friends in the insurance industry around what is this going to look like. Many of the folks coming into managed long-term service and supports don't know this space, don't understand these services, and are seeking an evidence base in terms of where should the investments go, in particular in a capitated rate model.

>> Thank you.

>> Henry Claypool: Please join me in thanking the panel.

[Applause]

And now we'd like to turn to what is typically Andrew Houtenville's kind of closing remarks. As you all heard, unfortunately, he wasn't able to join us, but we have David Wittenburg standing in for him from Mathematica. Thank you, Dave.

[Applause]

>> David Wittenburg: So I probably have you sitting there wondering he's got the last name of Wittenberg, so hopefully he understands that brevity is the soul of wit.

I will try to be brief, but I have a few closing re, ma. We started the day with Deb giving an overview of what we have in terms of data with the compendium. We ended the day with this roundtable, which is really about program and policy innovation. Those I think are the two themes that I would like for you guys to take away from this overall conference.

Sandwiched in between them, we had Ellen's talk and Lisa's talk about the potential budget challenges that we had. These challenges create unSeptember for everybody. They make people feel -- uncertainty for everybody. They make people feel uncomfortable, and precisely uncomfortable because they are uncertain.

On the one hand, social progressives may say there is a lot to lose, particularly if these programs are cut. You're going to cut services for the very vulnerable populations and what is going to happen to those programs? If we know anything about history, what we will see in media reports, people get cut off, there will be media reports, outcries and restoring of funding.

Fiscal conservatives are we making the right investments in these programs? I think the problem is we go around and around on these issues, and both parties may be right, and the problem is we don't have a sufficient evidence basis to really know what to do, in part because we don't have the right data or we don't have the right innovation.

There's also another fear here without that lack of data and innovation, and that's a fear of failure. If you take a look at the private sector, places like Google run thousands of experiments each year. A lot of them fail, but some of them succeed. Social programs don't run thousands of experiments. They run very few experiments, and there's a very big fear of failure in that.

In order to progress in many of these programs, we have to adopt a fear of failure. I've got no fear of failing right now. I'm speaking off the cuff. Hopefully, I'm not failing right here at this end.

This leads us to the panel, and what I thought was invigorating about the panel is each of you touched on these issues of either needing more data or needing more innovation in order to develop the evidence basis to have a logical discussion in a nonrushed discussion about what are the budget priorities, so that we can have a more relaxed dialogue, so we don't run into precisely the issues that Ellen mentioned, which is we make some sort of drastic cuts without the proper evidence, and we do something we wind up regretting and wind up reversing.

So how do we move forward? Some of the things to summarize this panel, I'll do my best to be brief, Sharon, one ever the things that I really took away from your talk that I found very exciting was the idea of developing quality measures that in order to make progress you need to know what is the quality of care. I empathize very much that's hard to measure, but that's just because it's hard doesn't mean you shouldn't measure it. You should continue to start to measure it, and probably going to fail initially, people aren't going to like the measures initially, but that doesn't mean you shouldn't continue to proceed with those measures, because that's the only way we're going to it make progress.

John, you talked about really the importance of employment. Not only just the research basis of employment, but the importance of technological innovation in terms of promoting employment. Things like driverless cars, I know you were talking about transportation innovation, but I got really excited about the driverless car for myself. But innovations with the crowd. It's not just research innovation, but also the technological innovation that supports the employment of people with disabilities.

Janet, in some ways, you have some of the more difficult responses as you talked about WIOA, because you are implementing, you're working with a legislation that is going to represent fundamental shift and also a very quick shift for states to develop plans, and there's going to be an interaction of systems. You hit on the right notes of encouraging flexibility for states, and also having the appropriate technical assistance so that states can be pointed all in the right direction. But as you go forward, I think one of the points is to make sure that states have the evidence basis to know how to move forward, what are the employment rights, what are the VR service rights within -- what are the effective practices? Are some states doing better than others? I think leveraging the different states and learning from some of the best state examples would be ideal.

Dylan, you talked about both the 503 provisions, and I thought the number of nearly 600,000 people getting new jobs was particularly interesting from Section 503. But also the emphasis that I took more away was on innovative competitive employment, which is really a refreshing emphasis. This wasn't necessarily the emphasis even a decade or two ago when there was strong emphasis that this was the right direction. So there is this refreshing move away from sort of a sheltered employment setting to more competitive integrated opportunities, recognizing people with disabilities as part of the mainstream society and continuing to move along the themes that were initially established in the ADA.

Finally, Robert, your discussion about Social Security and the program operations and even just the name of the website that are trying to align resources for those that are on these growing programs with work opportunities, calls Choose Work, I think is really, really important.

In conclusion, I leave you with both the idea of data and innovation. I want to leave you on a positive note, because I know there is this larger budget uncertainty. As you deal with these uncertainties and you have conversations with them, arm yourself with knowing what we should be doing, we should be doing things based on evidence basis, not a feeling basis. If we do things based on evidence basis and a cultural of innovation, we will have much greater chances to succeed.

So I leave you with that, and hopefully I haven't taken up too much time. But I'm happy to close out. I want to say a special thanks to Deb Brucker who coordinated all of this, and I believe also with Lisa Ekman, your team for putting together the panel. And penny Gould who also was very kind enough, not only to give us this great space but all the extra food that you're encouraged to take home afterwards.

So Deb or Penny, anything? No? We can close out. All right. That is it for this year's event.

[Applause]