2015 Annual Report on Disability and the
2015 Annual Compendium on Disability Statistics
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Onsite Captioning

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>> Andrew Houtenville: Hello, everybody. Can you hear me OK? I'm assuming that online people can hear us. Is there a way to confirm online is hearing us? Are we good to go? A few people online.
We're waiting to get the heads up that online is a go. I get the thumbs up. We're ready.
Thank you for showing up today on this warm and balmy DC day. I have Sue Fox here with me, Lewis Kraus, Lisa Ekman. For those in the room, some logistics. Restrooms are behind us. Women's are on the right, men's on the left.
The food is available, if you're interested in going to get food. The internet password is SP 2009 TWC, all caps.
For those of you online, you probably know where your bathrooms are.
[Laughter]
The food is on your own. Your internet, obviously, you're on the internet so you probably already know your passwords.
Today, we're going to -- it's in two parts. We'll be talking about the compendium and the annual report, and in the morning, then in the afternoon we'll be hearing from the agencies who collect data. We have people from CDC and Census, and we also have someone from NIDILRR coming as well. Welcome. All welcome. Wharf we'll try to leave as much for Q&A as possible. We've had a good tradition of a long time for Q&A, and so I'll go ahead and introduce the agenda. I'll introduce the compendium results.
Sue fox from the University of New Hampshire will talk about some topics related to aging and community living. One thing, if you're not familiar with NIDILRR, National Institute on Disability, Independent Living, and Rehabilitation Research, formerly known as NIDRR, they've moved to the Administration on Community Living. A big part of the Administration on Community Living is the aging programs.
So we're going to bring Sue, who leads the University of New Hampshire Center on Aging and Community Living and is also part of the University Center of Excellence on Disability, UCED, for us. She's going to talk a little bit about the issues around aging, some of the patterns she's picked up in the compendium, and some of the issues that may be facing disability and aging statistics as we move forward, because that presents a real nice forum for people to merge aging and disability statistics as one form of language that we can use to cross those silos.
Lewis Kraus will talk about the annual report. The annual report can be viewed, Lewis is holding it up, the annual report is in some sense an executive summary compendium.
I'm going to do time trends. Lewis will focus on distribution across states, geographic variation.
Then we'll hear from Lisa Ekman. Lisa will give kind of from the advocates perspective. Lisa works with the American Association of People with Disabilities and she'll give kind of a discussant role.
Then we'll go to Q&A.

That's the agenda for today. I'm going to jump right in. So my name is Andrew Houtenville, I'm the director of the Rehabilitation Research and Training Center on Disability Statistics and Demographics, funded by the national Institute on Disability, independent living and rehabilitation research, NIDILRR.

We've run the statistics RRTC, disability statistics center. We primarily go out of the domain on the web research on disability or disability compendium.org. Research on disability will get you to all of our NIDILRR funded work. Also get you to the work from Brian Armour, talking later from the CDC in Atlanta.

One of the things I will focus on are over time trends. So how are we doing as a population, how is the population with disabilities doing in terms of things like employment, poverty, Social Security beneficiary status, things like that. We're coming to a point in the recovery from the great recession where we might be in a growth period or beyond. We're kind of getting back to where we were before. But it's been slow going for the recovery from the great recession, and we'll see some results that speak to that slowness of rebounding from the great recession.

So I didn't do this.

[Laughter]

So Star Wars. I'll go back to it. Deb started it. Penny put that in. I put Deb as Princess Leia. I tried to do Jarjar Bings. It didn't come out well.

If you've been around disability statistics for a while, we've moved from one question and a lot of surveys, the amount of work you can do, the census 2000 expands that with six questions that were designed, then there's work to refine those six questions leading to the 2008 revision. The ACA, there is a little provision there that says all health surveys funded by the federal government has to use a core set. DHHS picks up the six questions used in the ACS as that minimum standard. We now have a minimum standard similar to other demographic categories.

Disability moves away from being a health issue or outcome to becoming a demographic population. Right? So there has been a real great movement. I'm going to get rid of that picture.

This is the 7th annual compendium release. That's an awesome number. I'm a "Game of thrones" fan. How many are game of thrones fan? We're at the University of New Hampshire and funded by NIDILRR.

So the purpose today, we'll talk about the compendiums, talk a little about the new tables. The basic overview, we've added a lot on aging. We're trying to bridge that gap and integrate with other programs and provide information to the other programs at ACL that may be of interest to other grantees and other programs at ACL.

Then we'll talk about how to access technical assistance around the compendium.

The purpose of the compendium, it started a long time ago. How many people know the US statistical abstract that Department of Commerce puts out? It's this great, thick, no longer in print, I'm not sure they're updating it anymore, but it's this great resource that I used to flip through it and polish, go to the reference library, they'd have stacks of the books in the back. There was not a single disability table in the document, even the most recent version. Not even a disability program on Social Security programs, which is phenomenal to think about.

We wanted to provide that to the community, to pull together all different data sources. That was a big part of it. The compendium is this huge mash-up of all published statistics. We started to develop statistics that we estimate ourselves using the raw data itself to try to fill the gap for what the agencies are not providing. We want it to be readily accessible so we do a paper version. People still want to flip through. We do an online version. We do a big PDF version so it is searchable, accessible.

We've moved towards developing annual report to try to give a quick summary.

So it's really a comprehensive set of tables from existing publications. It's linked to the original source. A lot of times the sources have a lot more information. One thing I used to use the abstract for is find something close to it, then go to the original source. Because the statistical abstract of the United States was this massive mash-up of all federal data sources and some international sources.

Also at the bottom of the compendium each page is a 1-800 number, and e-mail address. Just to get people, because a lot of times people know what they want, they just can't find it. Google is getting a lot better. It's all advancing. But sometimes people need to know it doesn't exist, because you're looking for something very specific. A lot of times you say, Oh, I've never run across that. I don't know a data system that will tell me the number of people with hidden articulation issues in a county. Which might sound trite or very specific, but when you're buying punch cards for the, back when all the technology, the voting was changing, hand articulation issue and hearing and vision were really important, having a very finite level, to be able to buy the right equipment and represent that population in your area.

So people were looking for things that just don't exist. Having a 1-800 number, yep, you're right it doesn't exist, as far as we know. That was helpful.

We do focus a lot on state level. We're in the process of developing a big website that will allow people to get county and city and local statistics, so every compendium table you see on the website you will be able to click and drill down to your location. Well, most of the tables you see. Not all. Because some are still based on small sample sizes that are just national-based statistics.

But you will be able to see. We'll probably have a marker in the compendium in the annual report to say this data set you can drill further for geographic location, have a little map or something to indicate that.

The topics are really if the federal government produces it on an annual basis, sometimes even nonsystematic, periodic basis like the survey of program participation, we'll put it in there. If anybody has anything they can recommend, we'll be happy to do it.

We did expand by age, but if there's a topic where you know that they're developing a systematic way of reporting it, that we can depend on every year to refresh it, let us know. We'll be happy to consider it for addition to the compendium.

We have disability type, international patterns, government spending, the folks from Mathematica developed the spending project several years ago. Periodically it is updated. Probably one of the most intensive, difficult things to develop, the spending on working-age people with disabilities. We're hoping to expand to spending on children and older adults.

We have special education, vocational rehabilitation, Social Security programs, health and behavioral statistics coming from the behavioral survey, the CDC in Atlanta, the veterans and poverty, employment and earning statistics from the Census Bureau with the American Community Survey.

We have long-term time trends from the current population, annual social and economic supplement and we have long time trends. We have monthly trends from the current population survey based monthly survey. Some of you may be familiar with our program, the program with the Kessler Foundation in New Jersey, and we report monthly statistics. I have a couple slides on that. Wharf what's new, we've broken out age ranges, expanded some time trends. More detailed sections on introductory text and examples. We've expanded and upgraded the glossary. We've added a frequently asked questions section. People have questions that they think should be frequently answered, that people should be aware of, like the definition of disability, things we should add, anything we should add please let us know.

The biggest caution goes to that frequently asked question is the definition of disability, the data sources, even if they're using this standard, they're still going to be variations, so that the Department

of Health and Human Services minimum standard, the six questions for the American community survey is being folded -- not rolled out into a lot of different sources, but you still get different numbers. You can all expected a range, as David said from NIDRR. You have to accept a range. Now, what you want to do is pick your data source so that it meets your needs as best as possible. If you contact us, we can help you do that, if you have more than one estimate.

Suppose you want to use an estimate, you said OK, I want to do Chicago, then I can go get that. You might not want to, because year to year you have a lot of variations. Might want to pick the American Community Survey.

The other big caveat is around employment statistics, unemployment. Unemployment is a very specific thing. Be careful about that. The unemployment statistic is an old statistic from the 30s that really is about the tightness of the labor market, not necessarily how a population is doing.

We use the employment-to-population ratio, the percentage of people working or the labor force participation rate, to look at what percentage of the total population, not just the active population, percent of the total population. So we always steer clear of unemployment for that reason.

Size of the disability population, so this is out of the American Community Survey, table 3.1 -- or 1.3. We're at about 4 million living in the community. Does not include people in institutions, which is probably an additional 2 million. 2.5 million if you include people living in institutions, both disability related and things like prisons.

You might say where is the 54, 56, 58 million I've always heard. That is based on a different data source. This is based on six questions. The 54 million, 56, 58 million, one is based off the survey which asks about 16 questions. So a lot of people have a difficulty translating this. You used to hear 1 in 5. 12% is not 1 in 5. It's 1 in 8.

So that's why we have a section that provides the SIP statistics, so people can go to that if for your advocacy purposes, if you're running into problems with this. You have to look at more resources and find the source that works for you.

How has this looked over time? It's been rising over time. This is not age adjusted. This could be the baby boom. Disability still is very much something that's related to age. We have people who have -- we're online?

>> We're fine.

>> Andrew Houtenville: Should I say anything to the online people?

>> We're working on it.

>> Andrew Houtenville: Did the glow off my forehead? I forgot the powder this year.

[Laughter]

Did it break it? You're on that one. OK. They're fiddling with the camera back there.

The population fairly stable at the time, but still growing. You have the natural size of the population growing over time. But we're still at about 39 million, maybe a little step down this past year. It's an interesting question. It's likely statistically significant, since these are large sample sizes. This is again self-report. So there's a possibility that things in the environment are changing. As the economy improves, people aren't getting jobs, they might not feel limited. This is not whether you have a health issue, it's whether you have a disability, which is a combination of the environment and health.

When we look at the disability types, with so we have the total percentage at 19.8, the ambulatory, so mobility, do you have difficulty climbing or walking -- climbing stairs or walking? Ambulatory is the largest, followed by cognition difficulty, thinking, difficulty remembering, concentrating and not making decisions. Is it still making decisions? I remember it changed.

Followed by hearing and vision, relatively small. Also the independent living and the self-care. Self-care and independent living are quite different. They're very much activity limitation based as

opposed functional status, the ability to form basic functions. It's most likely that the people with ambulatory, vision, hearing and cognitive are a subset of those have difficulties with self-care and going outside home alone.

Not everything with a disability faces limitations. There's accommodations, there's the environment, you may have difficulty hearing, but you may have figured out ways or the environment has adjusted in ways in which you're no longer limited in your ability to go around or do self-care activities.

In terms of employment, the employment rate is always varied quite a bit by disability type. The hearing population so that the employment rate, the percentage of the population that are employed, this is also known as the employment population ratio, the percentage in the United States is around 75 for people without disabilities. For people with hearing impairment, hearing difficulty, it's 50%. The next is vision, with 40%. Next ambulatory is 24.4%. I think that's one of the more astounding things, you think about the ADA and lots of things that have been improved with path of travel, it's really kind of surprising to see that cognitive and ambulatory disability, or ambulatory difficulties are similar. Maybe people with mobility difficulties are saying, No, this is what we -- Lewis and I talked about this. I'm like yeah, the ADA has been around so long. Come on. You still have to fight fights for certain things, like bathroom modifications at employers. Still not a straightforward thing.

The overall disability population is 34.4. 34.4, this is the employment gap we've seen, how are we doing over time? Great recession, if you remember from last year the big question is whether people with disabilities are recovering from the great recession. I think people have tracked like the great recession and the issues around growth and things like that. What are the two big issues? Wage growth is not following employment, and people over 50. Particularly men over 50 having a difficult time. That's what you hear in the general population statistics.

So if men over 50 are having difficulty reentering the workforce after the great recession, perhaps that might be signaling something in terms of the way firms are hiring individuals.

So the employment gap over time. So probably there are two things to pay attention to. This graphic starts in 2000, right at the great recession, with I was really February 2008, August 2008 were the two big job loss months. So if we had 2007 data, it's unfortunate we don't have 2007 data for the ACS, six questions, we would see higher for the overall population and a much bigger decline from 2007-2008, because we're really right at the great recession. You still see decline.

If you look at the blue, top number, you bottom out at 2010-11, then there's a slow creep up to 73, 74, 75.5%. So you see people without disabilities rebounding a bit.

People with disabilities, you see the same kind of fall from 39 to 35 to 33 to 32.6. Then it's kind of leveling out at 32. We've had a one-point increase, percentage point increase from 2012-13, then from 2012-14 we see another maybe half a percent increase.

So these are big samples, so highly statistically precise. You can quibble about how it's measured and how it may not be picking up people. This is not full-time employment. This is any employment.

So you're seeing a little bit of rebound, right? Now, when we look at the monthly statistics, oh, boy. When we look at the monthly, this isn't the greatest graph. This is the labor force participation ratio. This is the monthly statistics that comes out of the Bureau of Labor Statistics. Similar set of six questions, not the census, but census conducts this survey on behalf of the Bureau of Labor Statistics. It's difficult to see, because of the axis. I took the gaps or the difference between the two. What you see is a slow rise over time. You see a slow rise over time, a slow rise over time in the gap. So this is reflecting the fact we're seeing rebounding by -- some rebounding early in the great recession by people without disabilities, but people with disabilities were being left behind.

You see the highest period, this 2013 period right here, you see that high period, then you see a ratcheting back down. So in the NTIDE we were following closely, we had nine or so months of

positive numbers over the previous year, and we were like, Oh, wow, we're seeing a turnaround for the first time ever seen in any data. Usually what happens, people with disabilities ratchet down during recession, never recover, ratchet down at the next recession and I have a story, potential story for that. But -- a couple potential stories. You see this ratcheting down over time if we went to the current population survey statistics over time. You see this ratcheting down.

We've seeing a little recovery. Unfortunately, if you follow the NTIDE, the last three months have not been so good.

>> Do you have this with other demographics on the same slide, like African-American compared to white?

>> Andrew Houtenville: Good question. Do we have other at risk groups, perhaps, other populations, the same? I don't. I probably could get them though.

They don't -- this sample is still pretty small where they don't give big cuts. If they can did it for disability, they can do it for African-American.

>> Or male-female.

>> Andrew Houtenville: That can be done. I've seen male-female over time. You will semen lag behind in terms of the recovery.

So really this period of time here -- is that better for the people online?

>> Yeah.

>> Andrew Houtenville: You're sure? How am I doing on time? I think I'm going over. How far? Five minutes over?

>> We started late. You have about five more minutes.

>> Andrew Houtenville: OK. I've been told I started late, so I get five more minutes. I will try to speed it up.

Really, from the NTIDE, the jury is out. It sounds like people with disabilities were recovering. September was a bad month for the population, real big boost in the gap. So it will be interesting to see what happens over the next few months, whether the trend kind of starts to rebound or level off again. Or are we going to level off at this level? Is this where we bottomed out? Are we going to start recovering again? I think that's a really big question. There are two kinds of stories that are told.

One is Social Security applications. These are the number of applicants to Social Security Disability Insurance. This is in the compendium. We have the monthly number. If people are interested in Excel file, I can send that. You see a natural jaggedy thing. You see a real rise during the great recession. The middle of the graph is the great recession. You see a rise, you see a step function right here. So that's really a couple months after the big August dip. You see a huge jump in the number of applicants. Social Security is adding adjudicators very quickly to try to get on top of this.

So you see it starting to decline over time. That's great. People with disabilities are less likely now than they were during the peak of the great recession to apply. Now, what may be happening, why we see a ratcheting down every time, is we're still not back to 2002 levels. But what might be happening is Social Security pulls them -- people when you lose a job, if anybody has lost a job, what do you do? You try everything. You've got a family to support, you try everything.

Unemployment insurance is out there. Has a certain degree of time limited to it. Social Security doesn't have a time limit. It has continuing disability review, but people may be pulled into the program and stay there. Very few people once they go in stay out. You would see a ratcheting, natural progression that during recession people with and without disabilities lose jobs, people without disabilities go into time limited programs. People with disabilities go into the nontime limited program. I'm not saying the answer is to put time limits. I didn't say that. I know other people might. Who knows? I've never heard anybody say there should be a time limit out there other than continuing

disability review. It really suggests there needs to be a transition that the demos that Social Security has been doing and our colleagues at Mathematica have been involved with, those are issues. I'll get off my soapbox now.

But this idea that people are being sucked out of labor markets, stay out of labor market, we're seeing a ratcheting down. If you look at the long-term trend, 20, 30, 40-year trend in the compendium, you really see a secular decline. It continues to go. It's a bit of a step function, stepping down, down, down with each recession. But it's really decline in the overall employment of people with disabilities.

The other reason for this, and it may not be during job loss, one reason why you would go to Social Security is a lot of attention is paid by carving out job, customizing job, supported employment, all these relationships that in good economic times are easier for firms to do. They have excess, they have need, difficulty hiring people. They carve out jobs.

During a recession, if everybody goes, how does a person with a disability re-create that experience? It could take a long time. Social Security is needed to bridge that gap. But they've carved out this job. It's no longer available. To redo that process will take time. We expect if that's the case for there to be a log in the employment of people with disabilities. That will take a long time to recover. If there's not support during that process, they get stuck in a long-term program, that's not necessarily great at helping them move back into employment, then that's a real issue and why we would see a secular decline.

So it's really a story of, hey, you do all this great work carving out jobs, customizing jobs. If they get destroyed by recession, how do we pick that back up?

The annual report is next. That's going to be Lewis. So we have poverty statistics. We have Medicaid, Medicare statistics. We have special education statistics.

Please feel free to peruse the compendium. Lewis will give you more statistics. He's going to focus mainly on the states. With that, we'll do Sue next. We have to pull up your slides. I hope people online are doing well. I can't see feedback. How are they doing, Casey? Thumbs up. So everybody online is happy.

[Laughter]

>> They're informed!

>> Andrew Houtenville: They're informed. We hope so. Do we need to go out of presentation mode?

>> Yes, please.

>> Andrew Houtenville: Sue Fox, everybody.

>> Sue Fox: Thank you. Thank you. I'm very happy to be here this year. This is my first year coming to the compendium. I've been working with Andrew and his group for many, many years. In talking a lot about aging and I'm very happy that this year they added quite a few tables around aging.

So just to give you a little bit of information about me, I'm the associate director at the Institute on Disability and I also direct our Center on Aging and Community Living. We established that center about five years ago now. It's a collaboration between our institute, the Institute on Disability, and the sister institute at the university, the institute for health policy and practice. We found ourselves, both institutes, doing a lot of work in long-term care and aging and decided to kind of combine our efforts and establish the Center on Aging and Community Living. We were very happy to see that the federal government named their new center, or new administration, Administration on Community Living. We thought great, we were a little ahead of the curve on that one.

My background has primarily been in developmental services and mental health, but probably for about the last 10 years much of my work has been in the area of aging and so I have been able to really see how issues around aging and disability intersect, where they intersect, how they intersect, and kind of think about where we need to be going with that.

Done a lot of work with the Administration on Aging, particularly in developing our ADRC network in New Hampshire, and I think we've been able to bring a lot of what we've learned from the disability world into the world of aging. Likewise, learned a lot from the aging world about ways to help people with disabilities as they age.

So thought a lot about where those intersects are between aging and disability, and I really appreciate the opportunity that the compendium provides this year to start to get a better handle on the data around aging and disability.

Why it's so important now, I think we all know, we all see the demographics of our population. We're aging. That's kind of no surprise to anyone.

>> Andrew Houtenville: Some of us are.

[Laughter]

>> Sue Fox: Some of us are. Most of us are. Everyone is. Everyone is aging. But our population is aging rapidly across the United States. In New Hampshire we're actually one of the fastest aging states in the country. Actually Maine, Vermont and New Hampshire are all in the top six fastest aging states.

So it's been a particular issue for us to think about in New Hampshire. Really looking at two aspects of aging. One is the people with disabilities, with lifelong disabilities who are aging, living longer, and people who are aging into disability. I found as we first started working in the world of aging, even using the word "disability" around people who are aging, they were very offended by that. It took a lot of time to really work with the aging network and the aging advocates in our state to really think about the fact that if you're aging and now you have difficulty with mobility or vision or hearing or cognition, your needs are very similar to someone who has lived with those disabilities their whole life.

So we've been able to find some of that common ground.

There are a lot of similarities between the systems. Both systems work with people that are marginalized in our society, undervalued. Both systems are underfunded. You can argue developmental services system is better funded than aging, which it definitely is, but funding is always an issue. Both systems rely heavily on family caregivers. There's really strong data out there that 80% of long-term care services are provided by informal, unpaid family caregivers.

So both systems, if they didn't have those family caregivers, would be in a lot of trouble.

And both systems focus on self-determination, helping people living full, meaningful lives and have control over their lives. When I went into aging, I thought self-determination was a term coined in developmental disabilities. It was coined in the early 1900s in aging. It's a social work term. So it was kind of a nice learning for me that I think developmental services kind of took that term and developed its own sort of definition of self-determination. But it's been in the aging world forever.

In both areas people have a desire to remain home, living at home and in their community. So we have a lot of similarities that we can coalesce around between the two systems.

There's also some differences. In aging basically people become eligible for services based on chronological age. You have to be 60 or 65 of the federal programs. Where in developmental services it's more of a functional definition that gets you eligible for services.

Services and programs in developmental services are much more person centered, much more individualized and person centered. In aging, the funding flows down to programs and slots. So you get so many meals, you have to provide so many meals per year. You have so many adult day slots to provide. So it's still very much the funding still flowing very much from a program perspective.

In aging there's a huge number of unidentified potential participants. We know how many people are aging in our country, but we don't know how many people might need some support or some help to live at home.

And the funding mechanisms are very different. In developmental services we rely pretty heavily on Medicaid. In aging it's Medicare, Medicaid, Social Security, all of the Title V, Title III, all of the social service programs.

So the funding is much more diverse and fractured in aging than it is in developmental services.

So why is all that important? How have we developed -- I think of everything in terms of so what? What's the public policy that goes with this?

So in thinking about the public policy that is developed around aging and disability, it's really been lagging. I would say there isn't a strong public policy around aging and disability. Because of that, it's really kind of become de facto that it's local, regional, coalitions, aging networks. Not a strong public policy.

Part of the reason is that it's really fairly new that people with lifelong disabilities are living as long as they are. I think that it wasn't that long ago if you were born with Down Syndrome, you were likely going to die at a very young age because of a heart condition. Now that's just standard, that people with Down Syndrome, born with a heart condition, that gets fixed and that doesn't impact their longevity.

So people with lifelong disabilities are living longer. Historically, as we talked about, these two systems really haven't intersected much, and they have different priorities.

There's a big difference between the currently older cohort of people with disabilities and the younger cohort. In developmental disabilities we have a lot of older individuals who have lived in institutions much of their lives. They didn't have entitlements to services and supports and education. The younger group of people with disabilities coming through have had entitlements for public education and services and supports, the ADA, Olmstead, civil rights, human rights. There's a much different expectation of what people are entitled to.

I talked about the fact that people with Down Syndrome are living longer and we're finding a very high incidence of dementia, early dementia in people with Down Syndrome. Again, an effect of the longevity.

Some of the issues with how do we get a handle on all of this and know what's happening out there, what we can do about it, a couple of issues in the data. One is a lack of identifier for intellectual and disability. We have cognitive, but don't really know that the person has an intellectual disability. We don't have identifier for onset of disabilities. We don't really know how long the person has had a disability. So again, whether it's a lifelong disability or acquired.

A couple issues in the data that we need to think about. Getting into the so what, what do we do about that. I think it's really important we bridge across aging and disability. I think ACL, the Administration on Community Living at the federal level, has been a real leader in that.

But we need to build those relationships across at every level, at the local level, at the regional level, at the state level, at the federal level. We really need to build a stronger advocacy network for aging. Again, in developmental disabilities we have a really strong, particularly family advocacy networks that have a very strong voice.

At least in our state, we don't see that on the aging side at all. Cuts can be made to very fragile elder services and nobody says boo. You even try to touch the developmental services budget, families are marching at the State House door.

So we need to build a much stronger network for aging.

Again, we need to look for those common agendas that we can agree on. I mentioned care giving, home and community-based services. Technology. Technology holds so much promise for people with disabilities and people who are aging, to help support them to live at home.

My caution being to tread lightly. Neither side knows everything there is to know, and we really can learn. That's what I learned, we can learn from each other. Both systems have a lot to offer.

So I'm very happy that this year Andrew's group did add a number of tables related to aging, so we can begin to start to look at this data. What is it telling us? What do we need to do with that?

The age cutoff used for the compendium was 65. In our state, there's a lot of debate that 65 is not old anymore and that a lot of the analysis being done is really using the 75 as a cutoff for older. Then even 85. Because 85 is really where we start to see a much higher possibility for dementias. Some data says that there's -- if you live to be 85 you will have 50% chance of acquiring dementia or Alzheimer's.

But the compendium, the national data, uses 65.

The new tables in the compendium all have an asterisk by them. I did look through that, and I found 26 tables related, specifically having information related to aging, which is great.

Some of those areas are type of disability, looking at aging by type of disabilities; employment. Another thing in our state, why do we not look at over the age of 65 for employment? People over the age of 65 still want to be employed.

Poverty. Veterans. Obviously, we have a huge number of veterans over the age of 65, older veterans in our country.

Health insurance coverage and community living are the areas the compendium looked at.

So I would just present to the group, leave you with a question of really where do we want to see aging and disability policy headed? And how can the data help us to get there? How can the data help us meet our goals around aging?

Thank you very much.

>> Andrew Houtenville: We'll have time to ask Sue some questions. Let's get Lewis' presentation up and change to presentation mode. Lewis Kraus.

>> Lewis Kraus: Thank you very much. Hi, everyone. Lewis Kraus. I'm the deputy director on the center of disability, Public Health Institute. Also very happy to be here this year for the compendium and rollout of both the compendium itself and the disabilities statistics annual report. This is our second one. They are out there in front, if you haven't picked one up, go ahead and pick one up.

[Applause]

Oh, applause and everything.

>> Andrew Houtenville: I didn't get applause. What is this?

[Laughter]

>> Lewis Kraus: There you go. See! All right.

I hope you're going to be interested in and ready to look at some maps. We're going to be racing through the data. I'm pretty much going to cover every table, every page of the annual report. We'll do it very fast. So if you want to look at it again, make sure that you can have the actual book yourself to look through.

>> Andrew Houtenville: Or online.

>> Lewis Kraus: Or online. All the data is obviously from the compendium itself. OK.

This is a companion volume to the compendium. It presents statistics to address the following types of questions: How many people with disabilities live in the United States? Has the disability percentage in different age groups? What is the disability percentage for different types of disabilities? To what extent are people with disabilities employed? What are the earnings for people with and without disabilities? What is the poverty percentage for people with and without disabilities? Is disability status associated with percentages of smoking, obesity and binge drinking? This is a subset of the tables in the compendium.

The annual report follows the same format as last year. That was established by my colleague Sue Stoddard. We're highlighting state data and variability in disability data by states. Additionally, highlighting trend of data this year across several years. And showing differences by age ranges. So these slides are also, I want to mention as I'm going through these slides, these pretty ones, they're part of a slide deck that is available from the StatsRRTC and you can use them if you would like. They can be used together or individually if you want to be making a particular statement to someone about a particular thing. So make sure you can get to that on the website.

Looking here first at the percentage of people with disabilities am the United States from 2008-14. Andrew went over this a little. I want to mention again that over the past years, the consistency of the disability question that was asked in the American Community Survey allows us to look at the disability percentage over time. So the percentage of those with a disability range from the low of 11.9% in 2010 to 12.6% in the last years.

It appears to have risen slightly in the last couple years. As Andrew said, this data is coming from -- while this is from the American Community Survey, there are other surveys that have other publicized rates of disabilities. The rates are affected by survey question, method and other factors. Each has their strengths and weaknesses, comparing between the surveys is usually discouraged by all the organizations. And we're using the ACS due to larger sampling consistent year-to-year questions and multitude of available to examine.

Here's our first state map, the map with every state highlighted. In all of our state maps we're dividing the data into core tiles, and they are color coded from light to dark to equate from low to high percentages.

Here is the civilians with disabilities living in the community as a percentage of the US population by state. The state with the lowest percentage of US population having disability was Utah at 9.6%. The state with the highest percentage of disability, West Virginia, over twice as high, with 19.9%.

For the most part, higher percentages were clustered in the southern US around lower Mississippi River region in the dark red with concentrations high in Maine and Oregon.

This is not surprising. You've seen this many times before. It hasn't really changed over time. But I do want you to kind of recall this as we go through this, because you will see some things match with this, some of the measures we'll show match with it. Some don't.

If we look at the age distribution of disability in the US population, Andrew showed a little about this. The percentage of people with disabilities grows as we know very well. The population under 5 less than 1% had a disability. Those age 5-17, percentage was 5.4%. For age 18-64, the rate was 10.5%. 65 and over was 36%. So it rises, it's rising rapidly with age.

If you look at the age distribution of US population of citizens with disabilities, this is the composition of the population of persons with disabilities in the US by age. Over half, 51.6% were people in the working age population. That's 18-64. 40.7% were 65 and older. Then disability in children and youth accounted for 7.3% for the 5-17 and 0.4% for the under 5.

I'm going to use this four-map slide style for you to get a sense of the image, the visual impression of what's happening as we change age groups.

So in the upper left-hand corner will be the 0-5 age group. In the one on the upper right corner 5-17 age group. Lower left will be 18-64. Lower right, 65 and over. So this is the way we'll show all of these.

Now we're looking at disabilities living in the community. In the upper left percentage of disability in children under age 5 is very low. 0.8% nationally, 1.9 percent or less in any state. The highest percentages in Arkansas and Wyoming. Eight states and DC have percentages equal or less than 0.5%. So very low.

As we see, we move towards a slightly older in the upper right-hand corner, ages 5-17, four states had a rate of 4.1%, Hawaii, Montana, New Mexico, South Dakota. One had twice that percentage, Maine at 8.2%.

In general, these percentages were grouped around the states around the Rockies and upper Great Plains, Hawaii and Alaska, more concentrated in the eastern and southern states.

In the lower left, 18-64, the highest percentages you can see them starting to coalesce now into the southeast. The percentages were lowest in New Jersey, 7.8%, the highest percentages were in the southern US, from Oklahoma to West Virginia, also in Maine and Oregon.

In the lower right for age 65 and older, we have that real strong movement into the south, nine states percentages were over 40%. Disability percentages were generally lowest in the Midwest and northeast, where 10 states had a disability percentage less than 33%.

>> Andrew Houtenville: So Lewis, we're moving kind of in a Z shape with age, start at the top, over, down, over.

>> Lewis Kraus: That's correct. That's correct.

>> I'm sorry, is there any life expectancy data? Are people in the south living any longer to equate for disability? Are there other regression analysis that you've done?

>> Andrew Houtenville: I can give some. No, there's no life expectancy data, but we can adjust for age in that way. Adjust for the age of the population. But if you look at a lot of literature on diabetes and stroke, it really follows the same kind of lower Mississippi valley, coastal Carolina. So a lot of aging statistics are probably following that similar kind of thing.

>> Lewis Kraus: I think what's interesting, I'm glad you raise that question, I do want everybody to realize that I'm just going to fly through this data. There may be many questions that pop up in your mind about why this is happening. That's exactly what we want to happen with these maps. We want you to think about what's going on and ask it and figure out what's going on, maybe it will inspire you to do particular research or get some policy dealt with. We're not, I think, trying in this method , or I'm not, trying to give you a reason for any of these things. But you can see some things start to pop up in your head about what's going on here? Why is this like this?

Did you want to ask a question?

>> I have quick comment. For the map that shows the children under 5 who have a disability, it strikes me that most of the states that have the highest numbers are the least populated states.

>> Lewis Kraus: That's a percentage, right? That's what's happening with the percentage. This is percentage.

>> OK. Thank you.

>> Lewis Kraus: OK. Now let's look at each individual disability. All of them are strongly associated with age as we've seen. Talking about hearing disability first. Very low percentages in the under 5 and 5-17 age groups. Rises to 2.1% in the 18-64. And jumps to 15% in those age 65 and older.

We look at those by state, no distinct regional patterns occur. Remember that pattern we saw in the south? We're not particularly seeing that here with hearing disability.

For those under age 5 with hearing disability, only four states had percentage of 1% or above: Wyoming, Arkansas, Montana, Nevada.

In the 5-17 age group, also Idaho, Oklahoma, Vermont, West Virginia were the high ones.

In 18-64, we have a low, we range from a low of 1.4% in Connecticut, Delaware, New Jersey to a high of 4.2% in West Virginia.

And then in the over 65 a concentration of states in the northwest and Great Plains. The highest percentage there is Alaska at 21.6%. The lowest in the District of Columbia at 8.9%. Those who live here don't get to say to me "Huh? I didn't hear you."

Vision disability, also rising. Up to 6.7% for those age 65 and over. If you look at those by state, again, those are starting to show that that typical conglomeration down into the south as we go in a higher ages. That's probably significant. I don't know if you want to know the numbers. The numbers are in the book itself.

For cognitive disability, same, similar kind of thing. Though a little less about the age going on here. 4.1% and 4.4% for age 5-17 and age 18-64.

Rises only to 9.1% for 65 and over.

We look at that by the age groups and we don't have an under 5 age group here in the data. So it starts with the 5-17 over on the right-hand side. Ranges from 2.9% in New Mexico to 6.8% in Maine. In the 18-64 group in the lower left, similar range, 3.0 in New Jersey to 7.6 in West Virginia.

In the lower right, the lowest percentage in Iowa at 6.3%. The highest percent in Mississippi at 13.2%. We're starting to see that pattern where the upper Midwest very low percentages, southeast higher percentages.

Ambulatory disability has a much different thing than we just saw with cognitive. It's really jumping as the age groups change, from 0.6 to 5.2% for up to 64, 3.2% force 65 and over.

We look at that by the state, again, we're seeing that classic pattern here of the coalescing down into the south as they age. Ranging from 0.2 to 0.9% in the 5-17 age group. 3.5 in Minnesota, 10.3 in West Virginia, and 65 and over you have this wide swath from New Mexico to West Virginia and Georgia with Mississippi having the highest rate, 30.8%. And Minnesota and upper Midwest and northeast having lower percentages, with Minnesota with the lowest, 18.2%.

Self-care disability, growing from 1.0 at 5-17, up to 8.4% at the 65 and over.

Look at those by state, you can see those doing the same coalescing down into the bottom, the southern states. This time, you are seeing a couple other unusual states popping up in self-care disability. California and New York this time are showing up with higher percentages.

Independent living disability jumping from 3.7% for the working age 18-64, up to 15.2% for those 65 and over. We look at those by the maps, again, this pattern is there. Range from a low of 2.3% in North Dakota to a high of 6.3% for West Virginia for that 18-64 group on the left. For the 65 and over on the right, 10.3% is the low in Wyoming to 19.6% in Mississippi on the right.

Let's turn to employment. Andrew went over this a little bit, where we see the dip here in 2011 of those who are employed and if you're looking at this, the left column or the orange column are people with disabilities, the employment rate for those with disabilities. The right column, the tall couple, are the employment rate for those without a disability. As you can see, the disparity is significant there. Something like -- not like, but here it is, 34.4% of those with a disability were employed. Those without disability, that's 75.4%. More than double. 41%, percentage point difference in the last year.

If we look at that for employment rate by state, these maps are a little bit different than what you saw. On the left-hand side now you are looking at those with a disability. On the right-hand side those without a disability. Because the core tiles are within the same group, the with or without disability group, you're not going to see a comparison of all this disparity in the rates, but you are going to see that the employment rate within them and what the states are doing within them, that is similar. That's what shows up here. In fact, the employment rates for those with a disability and without a disability kind of track with where those without disabilities are. Except for a little bit there in the west, with California and Nevada.

>> Are there any other indicators to this phenomena here? Is it because of the services to, or transition services from education to employment? Are the states being, or private industries being more focused on bringing them on and working?

>> Lewis Kraus: I'm not going to be able to give you a direct answer, because we need to do the research to find out that. That's a research question. You can imagine here that there's probably state policies that are involved, in one way or another. There might also be, depending upon the state, industries that are more or less likely to be involved in one way or another.

>> Andrew Houtenville: The Social Security Disability Insurance, SSI patterns different by state, and that will drive some of the employment differences. Also one thing to remember is that this is not just people with early onset disabilities, this is people with late onset disabilities. So some states who have industries that are very good at producing people with disabilities that put people in harms way, like the chicken-cutting plants in Arkansas, things like that, you actually see high disability rates, but also sometimes higher -- lower employment gaps because their disability is related to work, and people stay employed in some fashion.

So it's a bit of the industrial composition mix that can play. A lot of times it's really Social Security policies that can be involved.

>> Lewis Kraus: Let me add to the gap part. I did not want to mention this. In 27 states, it was greater in percentage points. The highest were Maine, District of Columbia, Kentucky, West Virginia. The smallest in North Dakota, 32.1%.

>> Do you have a chart for that?

>> Do you have a chart with the gaps?

>> Lewis Kraus: We don't have a map in the an rule report on gaps for this.

>> Can you add one later?

>> Lewis Kraus: We can create one, if you want. Yes?

>> Lewis, in terms of the definition of who's working for those with disabilities, is the work competitive integrated? Does it include sheltered workshops? Is it any kind of work?

>> Andrew Houtenville: It's any kind of work. It's self-supported. No, we cannot separate between integrated and sheltered workshop in the data.

>> Lewis Kraus: This is still ACS data. All self-report and it's not going to be programmatic data.

>> Andrew Houtenville: We do wish we had that ability, but --

>> For the folks on the panel, if you wouldn't mind for the people online if you can repeat the question back.

>> Andrew Houtenville: The question was does the employment measure represent people in supported employment or sheltered workshops or competitive employment. It's self-report so we can't tell.

>> Lewis Kraus: All right, let's look at a couple of other things. You've seen this graphic from Andrew as well, the different rates of employment by type of disability, with hearing having a 50%, 50.7% employment rate, going all the way down to self-care at 15.4%.

Here's median earnings for civilians with and without disability, age 16 and over. For those with disabilities, 21,232. That's about 2/3 of the median earnings of people without disabilities, at 31,324. That disparity of over 10,000 median earnings between those with and without disabilities continues a trends that you can see that's existed since 2008.

>> Andrew Houtenville: This is for people who work full time year-round.

>> Lewis Kraus: If you look by state, the range of median earnings in states was 16,322 dollars in Montana to Alaska, to those without disabilities it ranged from $25,515 in Idaho to $47,450 in District of Columbia. No real patterns there, right? In the visuals.

The gap here is one where we do have the gap. There is a median earnings gap in 2014 inflation adjusted dollars of the low gap was 4,390 in Alaska, high gap $21,603 in District of Columbia.

Generally the states in the north had a higher earnings gap. States in the south had a lower earnings gap.

Let's look at poverty now. Poverty, as you can see from 2009-14, the poverty rate rose among people with and without disabilities. But for people with disabilities the percentage increased from 26.4%, that's the left bar, the orange bar. In 2009. To 28.1% in 2014. That's 28.1% for people with disabilities in poverty, in case that didn't hit home.

Seeing a high of 29.2% in 2012.

For people without disabilities, the percentage went from 11.7% in 2009 to 13.3% in 2014. Just about less than half. In fact, the gap was over 15 percentage points basically. 14.5 to over 15 percentage points for this entire period.

If you look at it by state, we can look at it in different age groups, for those who are children under age 5, it really looks like the south there with a disability actually around the Mississippi region. For those 15 -- 5-17, similar look.

For those 18-64, it's got a little bit more going up into the Ohio valley and Michigan region.

For those 65 and over, a lot more in the southwest now.

Then generally, a couple quick slides here on smoking percentages. If you look at health kinds of data, smoking percentages, since 2009 the percentage of people with disabilities who smoke ranged from 27%, left bar in the orange, to 23% -- sorry, 27% in 2009 to 24.5% in this last year.

Those without a disabilities, 16.7% down to 16.3. More smoking in those with a disability.

Smoking percentages by state, they look fairly similar. So where there's smoking there's going to be smoking.

Obesity does a similar kind of thing. The obesity percentage for people with disabilities is 367 -- went from 36.9% in 2009 to 41.1% in 2014.

Those with disabilities. Those without, 23.5% up to 25.2%. Much greater obesity issue in people with disabilities. If that wasn't clear before.

And by state you can again see like smoking, if you got obesity, you got it no matter who is there.

A good story, binge drinking percentages for people with disabilities don't seem to be involved in this as much. Went from 13.2% to 11%. Those without disabilities seem to be higher binge drinkers from 16% up to 17.5%.

And the rates of that, and I will leave you with this to think about why this is, it's higher in the north.

[Laughter]

All right. That's all for me.

>> Andrew Houtenville: Not New England north. Thank you, Lewis. Lisa? Lisa is our --

>> Is it reasonable to assume the higher age rate is there significant --

>> Andrew Houtenville: Repeat the question.

>> Lewis Kraus: The question is, let me repeat it so I've got what you're saying. You want to know if there's more people, actual numbers of people who are self-identifying as having a disability increases with age?

>> No, I know that a lot of people who are older who have mobility issues and other disabilities don't always self-identify. So is there an assumption that the rate of disability is higher, especially with those over --

>> Andrew Houtenville: That's a really -- the idea is that how are people self-identifying. The question is. It's possible that a lot of people with mobility impairments that are older won't admit to, or won't identify, with a disability.

There are also regional differences in that as well. As to self-report. So self-report has always been an issue. We do have a project that looks at Social Security patterns, like the disability belt from lower Mississippi valley to Appalachia for all kinds of age ranges and things like that.

Would it be fair to say there's undercount? Possibly. That's a question to be looked at. I don't know for sure. You're on the right track.

If you listen to "Prairie home companion" the bachelor farmer who has amputation or loss of limb, won't talk about having difficulties. It's just not cultural.

A friend of mine in kinesiology, the gentleman didn't report a mobility difficulty. He wouldn't say anything. His wife leaned over and said "Yes, he does of" then he uses the ramp rather than walking down the stairs. He refused to say he had difficulty walking down the stairs.

These are all self-perception. You're right to ask the question. People at Census Bureau who developed these questions ask people to try to minimize the degree to which there's kind of cultural or age biases in the way people -- it's still an open question, I'm sure.

>> Lisa Ekman: Good morning. I'm Lisa Ekman, from the American Association of People with Disabilities. My job is to react from the disability advocacy perspective to the statistics. Just a little bit about AAPD. If you're not familiar with us. We're the nation's largest disability rights organization. We promote equal opportunity, economic power, independent living and political participation for people with disabilities.

AAPD acts as a convener. We bring together, for example, members of the disability community and members of the technology industry through our technology forum to talk about ensuring affordable access to tech following for people with disabilities and to ensure that they can benefit from all that technology can do for independent living and economic Social Security.

We act as a connector, both in terms of connecting individuals with disabilities to employment opportunities through our internship program and participation in Disability Mentoring Day.

Then act as a catalyst for change through these activities.

Our advocacy is driven by the principles of community integration, economic participation and self-sufficiency, equal rights and political participation, and the right to quality, affordable healthcare

I think I mention these principles because when you start from these principles and trying to achieve those principles, unfortunately I think these statistics don't show us a lot to be happy about, from an advocacy perspective.

We haven't been making the kind of progress we might have hoped, maybe when the ADA passed. We thought we might see a big change in employment. Clearly, we haven't seen a change in the percentage of people with disabilities participating in the labor force. We haven't seen a decrease this poverty among people with disabilities. Some of those trends are looking in the wrong direction. I think there's a lot of reasons for that.

I think that assisting people with disabilities to become employed and stay employed is very complex. There are a lot of factors that will have impact on individual's ability to work and to continue to work. Because it is an interplay of state and local systems and programs, federal programs, you see a lot of things happening in recessions in response to recessions that will have impact on an individual's ability, with a significant disability, to go to work and stay at work.

For example, when state budgets get tight they restrict services. So if an individual needs transportation assistance and transportation assistance gets cut, that individual may not be able to go to their job anymore.

You've seen in the recession many state cutting back on their home and community-based services. You look at a state like Illinois. Where if you were on a waiver, a Medicaid waiting list to get on a waiver, they might have cut their slots. They might have reduced the ability to get the

employment-based services and supports you would need as an individual with a disability to go to work and to stay at work.

I think that you also have to look at employment, you have a number of different pieces interacting. Andrew mentioned how employers respond in times when the labor supply is abundant and they can choose.

One of the issues is we have the Americans with Disabilities Act, but it is extremely difficult to prove discrimination in hiring. So if they get a thousand applications for a job, and you don't even get an interview as an individual with a disability, discrimination might be happening, but you won't even know it because you might not get a response to that job application. Some recent research that was presented at SSA's disability research consortium shows -- annual meeting, shows significant discrimination in hiring.

I think the other thing you will see with people with disabilities as they age, we have a situation in this country where if you're over 50 and you lose a job, it's very difficult to get rehired.

Now, if you're over 50, you lose a job and you have a significant health condition, which limits -- which causes functional limitations, that's going to make it even more difficult. You may be subject not only to disability discrimination, but also age discrimination.

With those two things together, it's very difficult for an individual to get back into the labor force.

So then you look at do we provide enough funding to Equal Employment Opportunity Commission to do enforcement and to go after discrimination? That's another question about funding now at the federal level. The answer is probably no, we don't provide enough enforcement money.

When you look at kind of -- you have to look at the whole picture around employment. So there are a lot of pieces that are going to fit together and -- or have to fit together for many people with significant disabilities, which since the start of the session, haven't been.

We do see as the statistics show, somewhat of a rebound. I'm glad we're looking at employment -- or labor force participation going back up for people with disabilities, but the gap of over 40% between people with disabilities is still huge. We haven't really made progress from 20, 30 years ago, and for some folks it's even more difficult to get employed.

I think there are a lot of pieces to that story. So the first one is employer attitudes around hiring people with disabilities. That's another piece. There are still misperceptions and misinformation about hiring someone with a disability. Some employers are still afraid about getting sued under the ADA, even though most accommodations are very inexpensive and most people with disabilities don't sue. But there is still those kind of misperceptions we have to overcome.

You will see initiatives like what can you do for the Department of Labor, the think beyond the label campaign, and also AAPD is working with the United States Business Leadership Network on something called the Disability Equality Index. So asking employers to take a look at how inclusive is your workplace and how do you recruit people with disabilities.

So we have to continue to do those kind of things, because employers are a big piece of do people with disabilities work. Are they able to get jobs. Do they get a fair shot at the opportunities and at the outcomes for employment.

We've had a number of things happen at the federal level that may show some progress over the next few years. You see that we have the Section 503 under the Rehabilitation Act regulations that require employers set a goal of hiring and recruitment of individuals with disabilities and to document their outreach activities and their recruitment activities.

They were just implemented in 2014, so 2015 was the first year that federal contractors had to include disability in their hiring plans. So we'll have to see. This is, 2016 is really the first year where

people -- where employers are really digging in and OFCCP, Office of Federal Contract Compliance Programs, is getting data, and doing enforcement around Section 503.

We also had passage of the workforce innovation and opportunity act which creates a number of different opportunities for improving the employment outcomes. It creates a focus on youth within our vocational rehabilitation system and requirement to spend more money, 15%, on outreach to youth and in pre-employment activities. Hopefully that makes a change for youth and change the way employment looks for people over their lifespan.

We also see the integration of disability into the statewide workforce plan. So that it is not thought of as separate, but as part of the overall workforce system, which leads to a change in thinking about all of the workforce programs, and job training and retraining is an extremely important piece, ensuring people with disabilities, especially someone, for example, who is over 50 and loses their job, the industry went away. What are they going to do? They may have a health condition or limitation. What are they going to do now? We need to make sure that they are -- that that type of thinking is integrated into our workforce development system.

It should move us towards having that happen in states. It also requires much more outreach to business and working with business and documenting that and creating a relationship so that it will help overcome some of the misperceptions I spoke about a minute ago.

So there are things happening, but things like this take a lot of time and near overlaid with other pieces of service cuts, decreases in funding for services and things in states.

As Andrew said, there's a lag often in the recovery for people with disabilities, and some of these programs also take a lag in implementation in terms of making a change.

I think one of the other things that is really important is to think about, and the statistics are helping us to do this, disability over a lifespan. Nothing magical changes for someone with a disability when they turn 65. If they needed personal attendant care at 64, they need it at 65, they need it at 66.

Though some people may want to work after 65, many people have to work over 65. Some of our programs and services and supports around set up to allow that seamless continuing to work.

For example, the Medicaid buy-in program, extremely important for people with disabilities who are working so they can keep access to services and supports. Eligibility under one of the authorities ends at age 65. If I have worked and have been able to save and all of a sudden I can't participate in the buy-in anymore, I'm not going to be able to continue to get services, so I can't work.

So we need to think about the entire system and many things have happened over the last few years that have kind of set us back along with the recession in terms of ensuring the support, for individuals with working age with a disability across their lifespan to work, save and improve economic opportunities and self-sufficiency.

So that's my reaction.

>> Andrew Houtenville: OK. We're going to go for question and answer. At some point we'll get questions from the online folks, correct?

>> I just want to make an observation. First of all, the work you do is so important and so fantastic that I just want to say thank you for doing it.

[Applause]

It's really amazing. I want to say that the charts on page 45 and 46 are really exciting for me in the other book, because on slide -- on page 45 you can see the difference in employment rates between the states.

A lot of the charts you showed, there was very small variance between the states. But on employment, if you're in South Dakota or North Dakota or Wyoming you're twice as likely as a person

with a disability to be employed as somebody in a whole slew of other states, which says that it can happen, number one.

Number two, I want to request that perhaps you could do a slide that shows the gaps between the numbers on page 45 and 46 and to create a map and to put them in a rank order, because I know that last year's data people were really stunned when we did this ourselves at respectability and saw that Vermont and Maine were the worst in terms of employment gap, when I think people had the perception that Mississippi and Alabama, it's really bad there, but really it was in different states and that it really leads to different policy questions when you look at it by the gap between the labor force participation.

I just wanted to say that. I also want to say our organization, and I hope everyone else will be involved in this, is working on the workforce innovation opportunity act comment period, that the laws is new and everything has to put out their plan, and that there's not a single state plan that I have read that has the labor force participation rate as a built-in part of their performance metrics in their state plan, and that every state by law is taking comments, and any group, such as yours and everybody else who could send in comments, that they need to have the labor force participation rate as a key part of their WIOA performance records, because looking only at the unemployment rate, which is what they have now, is a tragic misuse of data, and it really serves our community very badly when that is the metric they use in their performance metrics.

>> Andrew Houtenville: Let me try to summarize for the audience, the online people. We have a lavalier mic? Sorry.

Jennifer's firm respectability.org, and a couple major points she made was that that the WIOA comment period is currently open and organizations and people need to comment, particularly around the metrics being used, using the unemployment rate is not appropriate, using labor force participation rate. And including making sure if statistics on people with disabilities are included, that they're using the right ones.

Jennifer mentioned that the gap, to look at the gap, and when organization is look at and mapping the gap between people with and without disabilities there was a big surprise that northern New England starts popping up, Maine, New Hampshire, Vermont pop up.

A colleague of ours, Joyce Manchester did a paper, that really shows staggering amounts of Social Security applications coming from youth in those areas, northern New England, and that it's a real -- like triple the amounts.

So something is going on with how individuals are finding out about the programs, when Dave, who is in the back, when he and I were talking a while back, when the decision occurred and children with disabilities could get onto SSI it's really an information sharing process that kind of spreads across the country.

So if northern New England is representing the future, we've got to really be careful of youth. We think about the ADA population. We also have the people introduced to SSI at an early age that do not transition into employment, but transition into long-term poverty on SSI, because you're just above poverty if you're on SSI as an adult.

If Zeble spread across the country, as people find out about it, perhaps this thing we're seeing in northern New England, which could be tied to information about these programs is that what we're going to see later on. It's a real concern. I'll jump over. The gentleman in the back raised his hand.

>> Hi, I'm Bob, a couple years ago I retired as senior advisor at the Defense Department. Been working as a volunteer for 20, 30 years now, helping people with disabilities find jobs. Every time I come to one of these conference is get more and more discouraged.

[Laughter]

The statistics are flatlined at best. I think there's got to be a revolutionary change in this country. A lot of people are not going to like what I'm going to suggest. But I think we're maybe at the point where if feasible people with disabilities who are unemployed should be required to work. It should be -- just a few hours a week to gain work experience, to gain skills. I've been working for years with disadvantaged folks, and I understand those are the two key issues.

This may come about in a red state. I would hate to have that happen, but I think that we're at that point where it's a radical change has to take place. We just can't continue with these flat line statistics.

>> Andrew Houtenville: Yeah, I have a -- there are conversations around Social Security reform where partial disability program would be implemented. Because really, people with disabilities are kind of in an unfair gain, that it's 0-1. You're on or off. People with disabilities are forced into a gamble: Do I go that this program with the potential of being stuck at poverty level or introduce my child to this program, as a parent with children?

That's a 0-1. Disability is not a 0-1. So we're basically leaving people on the margins out or in. And a partial disability program would require people who have ability to work to work. And still maintain a certain degree of support. So instead of saying they're required to work, let's just set up a system where we know that disability is not a 0-1. Have people who have significant disabilities have the supports, have people who have less significant disabilities, who still need support, to help remediate environmental issues and help remediate health and function issues.

So that's a similar approach. Because getting that work experience is tremendous. Internship programs overall and mentorship programs have shown getting people early, early intervention. You're not too far off where people want to go. It's just how to get the programs to move in that direction.

>> Lisa Ekman: I think it's important to be really careful when you think about this, because there are people, for example, someone who is over 60 with severe rheumatoid arthritis and a cognitive disability. Work isn't going to be an option --

>> If feasible.

>> Andrew Houtenville: It could.

>> Lisa Ekman: So I would say also that you're talking about spending a lot more money than we spend now. There are millions of people who have disabilities who can only work part-time right now. Think about the change in the economy towards contract employees, not hiring people full time that wouldn't be eligible for assistance under a partial disability.

I support doing that, but it's going to be very expensive and I don't think our current Social Security programs are the place to did it.

We in this country don't have a social contract about guaranteeing people any kind of standard of living, and having the conversation what you will end up with is something maybe like welfare reform, where you see people who don't really go to work but no longer have any assistance.

I think when we talk about this, supporting people with disabilities to work can often be expensive, often more expensive than income support benefits. It's the right thing to do, we ought to do it, but in our current political environment I don't see them creating a program that's going to expand spending. If you are talking about providing a partial benefit, what I think -- or requiring work, you will see a lot of people ending up with nothing and increasing poverty, as opposed to the goal that you have, which is to help people become more economically self-sufficient and decrease poverty, but I think we have to be really careful when we think about how we might implement something like that in the United States right now.

\>\> We've been too careful for decades and nothing has happened. I think there's got to be radical change.

\>\> Lewis Kraus: Also another issue, which is kind of a cohort, right, you've got people who are already in certain age groups as we've seen who have a disability and the issues of employment for them versus those who are coming into workforce, right?

Now we're getting into an area we haven't talked about here very much, the education system and how much they are being prepared in school for being gainfully employed. The kinds of jobs that are out there, the kinds of jobs that might lead to the internships and whatnot that Andrew is talking about. Are there systems within the education system that will actually have those kinds of programs in place when students are still students, and they have a system that will support them as soon as they get out of that system. We all know there's a cliff and a whole different set of systems, and now where do I go?

So there are different answers for different parts of the community.

\>\> I manage the opposition to get the money. I'm Robin --

\>\> People raising their hands, try to get the mic.

[Laughter]

\>\> I'm Robin, I lead the individual and family support programs at The Arc. I'd like to ask a couple questions of Sue, one more general question. We're interested in the issue of aging caregivers and adults with intellectual and developmental disabilities who live with them. I want to ask how we can get some of the statistics that we want. Is there any way to look at that population from what we have today or do we need to build something different to look at those families, where both of the people are -- obviously everybody in every family is, who are already in the aging cohort? There was a movie this year looking at a 92-year-old mother and 64-year-old daughter with IDD. So one thing, how do we capture who those families are? But also with that movie, we see the potential for the adult with IDD to become institutionalized at that point and that's -- sorry for the spoiler alert there. Then the adults with IDD are leaving you statistics. Is there a way to look at that?

Also is there a way to look at people with disabilities who are acquiring additional disabilities through the natural process of aging? Lisa said nothing magical happens if you're a people with disabilities when you turn 65. It may be magical as you acquire additional disabilities. Can we look at that through the statistics?

The other question that I wanted to ask, which is kind of different and more general, we're trying increasingly to look at those families and diverse historically underserved communities. Have you thought about ways to look whether the self-reporting bias is different because of cultural differences in those different communities?

\>\> Sue Fox: I'll turn a bit over to Andrew for some of that. Let me just say you've just laid out a great agenda for research and policy right there. A lot of great questions that we are definitely struggling with.

I don't know how we identify all of these family caregivers. AARP and the national care giving alliance put out great data and statistics about numbers, but it's kind of a general, they're making some assumptions about percentages of people who are care giving, which is quite high.

I think that the group of parents you're talking about that are sandwiched, many of them, sandwiched between caring for aging parents or aging relatives and still caring for an aging child with a disability at home, I don't know how we find those people. They are the Mimis and Donnas. I did see that movie. I was on a panel that our public radio station put on.

The outcome of that movie was so disturbing because the adult child, the older child with the disability ended up in the nursing home, and did not fare well there. And the mother was so distraught having to have her daughter move out of the home.

To me, the simple solution in that particular instance was getting supports into the home to support both the mom, who is aging, and the adult daughter who is aging. Just seems so simple and easy but can't be done because our systems are not set up to do that.

Getting the information, who is out there, what the aides are. It's critical. The outcome for both mother and daughter in that movie were bad. I think it's happening over and over again. It was so much more expensive. The outcome cost the government a lot more than if they had let the two live together at home.

You raise really great and important questions that I don't know how to get at.

>> Andrew Houtenville: Identify the population with intellectual disability, it's really not possible. The survey was the one that asked the direct question about intellectual disability and it's in funding limbo and redesign. It's unclear whether they'll be able to successfully implement that for disability which was so valuable to many people doing research.

It really is an advocacy issue, not a data science or data issue. The population with hearing impairment and visual impairment were able to get the Census Bureau to split that question from hearing, from joint sensory question to two separate questions.

Similar for the cognitive disability question, which kind of inflates mental illness and a certain degree of advocacy is needed to basically get the surveys fixed. The centimeters at those questions.

So it's an advocacy issue, being in the right place at the right time to advocate for that data to be collected. With the hearing impairment people and vision impairment people can have that done, I can't see why intellectual and mental health can't get separate questions and more survey space. It's centimeter by centimeter decision. Julie Weeks has all the answers she'll tell you later.

>> Hi. I wanted to make one comment, then a question. For the folks that suggested that the answer is just to require people with disabilities work, I think what you're missing is that employers need more education. At the Office of Disability Employment Policy we did some research where we invited employers to anonymously come to an anonymous focus group with the facilitator and fess up as to why they weren't hiring people with disabilities. What they said when they didn't have to go on the record was, frankly, we think people with disabilities are suffering and it makes us sad to be around people who are suffering, and we don't want to have people in our workplace who are suffering. That's why we don't hire.

You know, I think that's very inaccurate information, but we got to get that word out there to employers.

>> Andrew Houtenville: Well, it's not inaccurate if that's what they think. What they think may not be inaccurate. What they're thinking may be inaccurate.

>> Good point.

>> Andrew Houtenville: One thing about that, quickly, with the -- we'll try to go for extended question and answer so people don't mind go without food for a while.

About that, just is a four-letter word. I don't think it was just do this. It's very difficult to make changes. So it's not just "just."

It's a chicken and egg thing. If they fear people with disabilities or feel people bum them out or are suffering, the only way to overcome that is experience.

I was in the 80s, I've told this story here before, I was in the 80s, women coming into the workforce, men had locker room talk, the men were uncomfortable. Men had to get over it. All these trainings about stuff. Men have to get over it. Now, I am a little cloistered in an academic environment, I'm sure

there is still locker room behavior, but that's not -- I'm sorry, I'm a man, it's not as much of an issue. Men are getting over it. If people with disabilities are stuck on programs, over 12 million people with disabilities, we're talking about a great deal of people with disabilities, 60% participate in some Social Security or disability or public program, they're not getting out in the workforce. So people with disabilities -- without disabilities don't have the opportunity to get over it. How do we move people off the programs in a sustainable, cost effective -- it's expensive.

Mathematica, Gina is here, how much is spent on working age people with disabilities with employment? 2%. Right? Spent on employment initiatives relative to income support. Right, Gina?

>> I can't remember.

>> Andrew Houtenville: Oh, she can't remember. She's aging. Come on. It was quite a while ago. Nanette is here. You did it. Like 2.5%.

I agree with both Lisa and your sentiment that there are difficulties. This is not easy. The idea of having an EITC, a wage subsidy as opposed to income benefit is one way to think about it, but the EITC is not without its issues, still is not, for individuals, going back to welfare reform.

It's not just a four-letter word in my house, and it's a difficult issue.

>> Thank you. One quick question. I've heard two different things in regards to the percentage of children with disabilities and the population. I wonder if you had any data on that. I'm hearing that persons born with disabilities are surviving more because our medical care is better, so that the percentage of children with disabilities who are born disabled is going up. But I'm also hearing that they're also surviving with more severe disabilities. So there may be children who have very severe disabilities. There may be children who would have been disabled but aren't now because our medical care is better.

>> Andrew Houtenville: Yeah, so there is that issue of both adults with traumatic brain injury and people surviving due to the increase in emergency medical care and veterans have seen that with the treatment of head injury are surviving more and therefore aging with those disabilities.

I'm a child, not just because I act like one sometimes, but my mother, I'm my mother's child. So a lot of times aging with a disability, intellectual disability is parents taking care of their adult children.

Any statistics on youth, on children age 0-5, the survey literature really still needs to work on those. The questions that come from Census Bureau are more keyed on and developed with adults in mind.

So some work on youth questions still needs to be done, because there's quite a large special ed population that may not be picked up with functional questions that are asked on, say, the American Community Survey or other surveys.

I still don't trust any youth oriented statistics on the number of youth with disabilities. I think we still look at Department of Ed, special ed statistics. They're still pretty -- need work.

So with that I'll just stop rambling. I saw art raise his hand with a web question. We'll give the mic to you.

>> The ongoing issue about not surveying folks in institutions, Andrew, you did mention I think 2 million. I wonder is there literature that supports that estimate.

>> Andrew Houtenville: Yeah, there's census that did work with the ACS. It's a bit aged as a report itself. I think it's 2008. When you include around 2, 2.5 million if you include people who are disability related institutions and nondisability related institutions, like prison population.

Amy, you may have something to say about that.

>> Amy Steinweg: No, I don't.

>> Andrew Houtenville: You're punting? The collection of institutional data is still an issue. The ACS has a population about -- survey sample about 2.5 million -- 2.5% of the institutional population.

The file itself, the definition between a group or institutional group or noninstitutional group is kind of fuzzy. But there is literature on that. There was a study years ago, Mathematica did a study, and a paper from the Census Bureau on the size of that population. 2.5 million is like the 54 million, it is kind of thrown out there, but it is roughly that. Not surprisingly, it's dominated by the incarcerated population, where disability is a very high percentage. Todd and Dave Stapleton have a paper that talks about that.

>> Similar to --

>> Andrew Houtenville: Yeah, it's really about addresses and how you get to them, how you define them, how you get to those populations. Small group homes, it's unclear. My understanding has always been that really depends on whether there are services provided, how that's interpreted. Because all of this is self-report. How you define an institution is still something that needs to be done.

What I would say is advocacy doesn't necessarily need to be done in the data collection. That can always improve over time. It's on the reporting side. Can you find an American Fact Finder in the main Census Bureau's website for producing statistics. Statistics on the people working outside the community, in institutions. A lot of the data exists. It's whether it is published or not.

We're going to go to the online. Art?

>> This is from -- I'm paraphrasing. I deleted this twice. They had to resubmit. They're curious if there's any trends that you guys either know about or you know just from being in the field concerning persons with disabilities internationally. Is there any data supporting that?

>> Compared to the US.

>> Yes, compared to or just in general.

>> Andrew Houtenville: Out of the UN has been developing statistics. There's the Washington group, which has been active in trying to uniform, create uniform data collection. In terms of publications, probably the biggest one that I know is out of the EU, European Union, where they've had a longtime evident to harmonize the collection of statistics across the EU, under the statistics on -- the SILC program -- and living conditions, yeah.

The EU generates statistics on that. There's a real issue. So I think that you get just prevalence rates similar to the U.S. where we had 9% in New Jersey, 21% in West Virginia. In the EU you get 36 in The Netherlands, 9% in Greece. That has a real huge impact.

If you're picking up people with less and less -- as the size of the population percentage-wise goes up you're picking up people with more and more -- less and less significant disabilities and will have a higher employment rate. David and Bob have a paper on that in a book chapter we did where the broader your definition of disability, the more less severe populations you'll pick up and employment rates will go up.

So there really isn't I don't think a very cogent way of does cross-national comparisons.

The trend, we'd like to do the trend over time. We're working with people at the EU to do trends over time. That way you difference out the measuring issues a little bit. Again, those are going to be very short trends, because like the US the trends really go back to 2008 or so. They don't go way back. Probably Mary Daly at the Federal Reserve bank is the top person to talk about statistics and social programs. Mary D-a-l-y. Papers comparing social programs across several countries.

>> I'm Kirsten Rowe with the Virginia Voc Rehab Agency. Working with the policy body at the state level on adding indicators to existing scorecards, 10,000 point scorecard. We're delighted they're interested in adding data on employment for people with disabilities. Sort of a follow-along to what Jennifer said at the beginning. We think it's important to have labor participation data as well as employment rates. This body has been using and is more comfortable with the BLS data from the

population survey, but it's the our understanding those data aren't available at the state level. We think the next best alternative is ACS. But it's comparability issues between the data and the population as a whole and the data for persons with disabilities.

I wanted to ask two very related questions. Are any other good alternatives? And how can we help our colleagues and partners understand that it might be useful to consider creating parallel statistics?

>> Andrew Houtenville: I think you have the right idea, if you're using monthly and only go national with the BLS and state using -- I don't think that with respect to surveillance survey has samples, they're adding five, not including employment questions, but the behavioral survey might be an alternative source. But again, samples are going to be small, if you're doing this year to year you see variations simply because of sample, small samples. I think the ACS is still the best source to do state-level employment statistics. I'd love to have the ACS put out monthly estimates, but that will never happen.

>> Amy Steinweg: Pass on the word!

>> Andrew Houtenville: It's not designed to do it. Because of the way that -- it's hard to do a full national survey on a monthly basis.

I think you're using the right strategy.

What I recommend is not reporting them at the same time. The census used to have a big poverty release, they still have. The poverty and health insurance statistics in early September. That's why NPR covers it. That's when census reports to the annual statistical -- the ACS poverty and numbers will come now about a few weeks or a month later. When they did them at the same time, you would never see a Census Bureau employee sweat like they did when the poverty rates did with the ACS at the national level. So ACS is really the best for state. Still does great national, but you can get differences. Because one is in March, asking about the priority year. The ACS is about the last 12 months. It's done -- that's the right approach. Let's go to Julie Weeks patiently waiting. Or did we answer? Then to online.

>> My talk will include later on information about the measures, sets of questions that have been developed by the Washington group on disability statistics now adapted by the UN. They are in International Labor Organization surveys as well as in all the 2020 population sense us. There are papers online comparing those across countries based on those measures.

I also wanted to mention that we at the National Center for Health Statistics, which is one of the centers at the Centers for Disease Control and Prevention, are working with Department of Health and Human Services to evaluate the information that the national health interview survey gets on the intellectually and developmentally disabled populations. We do have estimates from that. However, this is a really big however, it's a learning point, it's also why these open comment periods that you see in the federal registers are so important, the legislation that defines the developmental disability, you have to hit 3 of 5 criteria and it has to have an onset before age 22. The measurement of some of the criteria that were written into the law is nearly impossible. So self-direction, a person has to be hit on that criteria, for example. How do we measure self-direction?

The criteria also picks up performance and capacity. So some of the questions are definitely capacity questions, and they track very well to our ACS questions. Others do not.

So the real issue is when we think about creating policy can we also implement questions that inform those policies? So often our questions here are, But what else? What about this group? Or so what? We always want to kind of go beyond to really get our answers, and I think the measurement issues and our influence on the data collections is really important. I'll be talking about the HIS --

>> Andrew Houtenville: Sounds good. National interview survey has information about that.

I just would underscore it's really an advocacy, being at the right place at the right time. When legislation is being passed sliding things in there to get funding. The big thing with this it's discretionary, not built into a specific program to be collected like the CPS or the ACS. So when it comes to Census Bureau priorities people will have the statutes right in front of them in their books. They want to be compliant to the law. So advocacy is really important when it comes to statistics. If it's in the law, they will do it. They will try their best to do it. Agency folks want to follow the law. If a program is not set in a given piece of legislation that you need to collect this data, they're not going to collect it. Not just the way to collect, but actually to collect it. It is an advocacy issue. I don't have the mic. I don't want to decide.

>> Going back online. An individual named Peg Nosic wants to know why gender has been ignored in statistical reporting on disability to date.

>> Andrew Houtenville: Yes, that's right. Peg, we added aging this year, and we looked at gender next year in terms of expanding.

You know, there is some institutional inertia about providing statistics for certain government programs by gender. BLS economists always divide things by gender. Always. Labor markets are quite different for men and women and it's an important issue in economics.

Having employment rates, I had to kind of when I first started doing disability, to kind of come to terms with that, because it was something that was inbred in economists to look at gender issues always. Health statistics to some degree, but population -- I'm sorry, program statistics like Social Security statistics or vocational rehabilitation statistics, it's not in there. They want to serve everybody. So when they won't produce, a lot of the statistics in the compendium are not available by gender. So Medicaid, a lot of latter sections. ACS gives a lot of things by gender we can use easily. BLS, yes. But the programs typically don't separate out by gender, not in what's published online. Some but not always. Like a plot of special ed statistics are not -- a lot of special ed statistics are not. A lot of Medicaid statistics are not. Some, but not a lot. Particularly when you get to the state level. They'll do it at the national level, but not at the state level.

Race and ethnicity, Hispanic, non-Hispanic race. Our penchant has always been to start with state, then disability type. Now we've added age. Same question about Hispanic and race. I think we'd have to start going away from state to do a lot of those, because you can't do state at the same time. It ends up being too big. The compendium is not supposed to -- it's kind of a guide to where else to go. So thank you again for that question, peg. We'll look at creating a gender section or rather than gender section, just put gender, male-female divides between, for all the things we tend to.

>> Carol boyar from the Office of Disability Employment Policy. I wanted to point out to a colleague from Virginia and others interested in state data on employment, ODEP just came out with this last fall a state-by-state guide on employment areas related to our employment first policy work. I think there's more than 35 states that are employment first states that is led between ODEP and now ACL permanently and working with us as well.

This is a really, really good state database for states that want to look up where their state fares with Social Security, all of that can be looked at. So talk to me if you don't know where to find it. We can help you with that.

I do want to make a really interesting comment about the obesity and smoking gaps between people with disabilities and people without disabilities. There's about 10% gap in the smoking and 15% gap with obesity. I work with a huge amount of federal agencies, more than 40 federal agencies and subagent sis, more than 100 Mississippi with the federal partners committee on women and trauma. We quoted you in some of our reports on women with disabilities and things of that sort.

What is interesting is obesity, especially morbid obesity, is very much related to trauma. That's something that all of us can take a look at, because a lot of people that are morbidly obese it's because of something that may have happened to them. We all know people with disabilities and women especially with disabilities are affected more by domestic violence and other people's violence against them, trauma, all of that has a great relationship to trauma. It's very interesting with the obesity numbers. It very much goes with the trauma related issues.

>> Andrew Houtenville: We modeled a lot of the compendium work off work that Nanette Goodman and Bonnie O'Day did for NCD years ago to develop a matrix of indicators and crime and violence are not represented in the national statistics very well. They're not covered under ACA because it's not a health statistic. But there is the idea of putting the same six questions from the ACS into crimes, crime surveys. So that's one area where we know there's disparities in victimization, that that needs to be addressed, and it's a gap in the statistics that are collected and published with disabilities at the national level.

With the obesity, if you saw Lewis', you saw the disability belt which stretches -- if you go by county, you can see it stretch down Appalachia into the lower Mississippi valley, hits coastal Carolina and some western counties in Oregon and Washington state.

We're going to do county-level statistics soon, hopefully next year we'll roll out a new website to get compendium-type statistics for counties.

The obesity. So obesity, obesity when you think of mobility impairment, it could be obesity. Think about back pain, it could be obesity related, diabetes related. As I mentioned earlier, the same belt, the diabetes belt, the stroke belt, all follow that Appalachia, lower Mississippi valley, coastal Carolina. A lot of statistics that we're seeing could be highly related to what we're seeing in the mobility statistics could be related to obesity, and we do have a project ongoing with the Kessler Foundation to look at the disability belt and underlying properties.

>> Lewis Kraus: If I can add one thing about the obesity. A couple of years ago you probably know Vince Campbell from CDC, who pulled up some data while we were sitting in his office. We looked at it, that obesity is high, is very high in disability and it is -- you don't want to make too much of a policy comparison here, but it's higher than any other group. It's higher than any race. Higher than any ethnicity. That's kind of a major policy issue that shows up. But you don't want to compare it, because there's valid reasons why obesity is important in those areas as well, other areas as well. But it's there.

>> Lisa Ekman: One other point to think about is the access that an individual has when they -- to healthcare and other services and I don't know if you looked at this, but sort of healthcare coverage in some of the disability belts. So for example, you get diabetes whether that becomes a disabling condition. When we're talking about people having better longevity and doing better, having better quality of life and ability to live independently when they have a disability, that is also influenced by their abilities to get good access to treatment. You look at states that didn't expand Medicaid, so people don't have access to healthcare. That can have impact. To think about when you think about trauma, access to counseling and other services that can help an individual to move forward. And disability is both a cause and a consequence of poverty. When you also look across Appalachia you see very high rates of poverty. Even if they have healthcare, they may not be able to afford a co-pay or get all of their things covered because of the fact that they're poor. So there's a lot of interaction among those things.

>> Andrew Houtenville: Yeah. I would do a push for onset information. Because it's both a cause and consequence. We really need to watch did people who have early onset disabilities as they move into obesity status, as they move into poverty status and it's not surprising that rates are so high. But we'll

go to the mic.

>> Rebecca shelved with the American Foundation for the Blind. First I wanted to say how much our field uses this information and how valuable it is and how easy it is for people to access, how often I see it cited. Thank you, thank you for doing what you do.

I also wanted to, this being election year, we're always reminded that the statistics that we choose to present have power. So we can't possibly present everything. If you could briefly tell me how you decide each year what you're going to focus on. Then I wanted to put in a plug for multiple disabilities and maybe it would have to be a web-based tool where you look at the intersection of, for example, someone who only has vision loss versus someone with vision loss and other disabilities that can be very different trends.

Then in addition to states, urban vs. rural areas is really important because I think there's trends there with the accessible communities that would intersect with employment. Multifaceted question, but again thank you for everything.

>> Andrew Houtenville: Sure. The question about what we choose to include, it's a lot of inertia. We want to have people able to use things year to year and inspect. We rarely reduce something. Then it's a matter of time, adding age statistics really was a very concerted, difficult process. There's a lot of moving parts as we built the compendium over time. Adding things like multiple disability, we may have to do that by ourselves, because the American Fact Finder for the ACS statistics doesn't do that. We can do that with the raw data. One reason we moved to February is because the raw data typically comes out after and takes a bit of time to work with.

The idea of a rural-urban split would be great. I wish that the urban planning and those people would finally settle on a definition of what's rural or urban. It's a bit of a moving target with that. We have definition of disability, they have definition of rural. It's complex and a moving targets.

Multiple disabilities would be really interesting, combination of self-care disability with the others and the independent living difficulty with the others helps us address the issue of severity and where pockets of severity may do. I really like the move towards county-level statistics, which we're hoping to. The ones this year were not ready for primetime. That's where a lot of policy is.

>> Lewis Kraus: Let me add about the rural and urban and also county-level data. That is something that Andrew had us work on as well. We've got some of that available. The maps that we've done, did by state, did by county too for some of these. That shows up really interesting. There might be a way we can share that online as well. But if you're talking about urban-rural, there is the data, the fact finder dig down into the statistical areas and also even zip code and we've done, we've worked with some local health departments in California to try to get them data in their county, broken down by zip code. We can do that. It is there. If you have something specific about it, you should give us a call and we can do that, help you do that.

>> Andrew Houtenville: We did work with, after hurricane, Superstorm Sandy with zip code data. Because the zip codes are so densely, they have big samples in New York City. We were able to do the zip codes in the areas right around the coastline. It was a coastal issue. We were able to look at the number of people with disabilities and various types at the coastal area, look at housing. We were able to look very closely at places impacted on the coastline.

>> I had a question about slide 54 on the -- in the book. As opposed to in this thing. This is the change --

>> Andrew Houtenville: This thing? It's the compendium.

[Laughter]

>> The compendium. The Bible of those working on this. Some states got much worse in terms of their employment gap. We see that Arkansas, DC, and a couple others here really had a significant, I

mean, New Mexico, significant bad things happening. I wondered if you have some observations on that.

I also wanted to point out that it seems very interesting to me that DC things got so much worse correlating with the time when there's now 503 for federal contractors and there's affirmative action at the federal government, how despite those two policy changes we've had this very significant things bad happening. I want to say in Wyoming I know it happened, which is that the government defund the Business Leadership Network. They used to have a BLN in 11 cities in Wyoming. That's being generous. They had 11 BLNs and the state defunded them. That's what happened in Wyoming. What about the other places?

>> Andrew Houtenville: Two things. The American Fact Finder has five-year moving averages, five-year sample for some of this. I would hesitate to look at a year-to-year change for a state with small sample like Wyoming. ACS is big, but it's possible this is sampling variation, not a statistically significant change, because it's not measured with a great deal of precision.

To be able to look at state-to-state changes, for small state like Wyoming it's not possible, but to look at the five-year sample. That's starting to come online for disability statistics.

It's also difficult to attribute changes, because there's a lag in implementation. You may expect to see large changes, but the BLN, sure that may have an impact, but I expect that impact to take time to be brought in, because employment is not as responsive as other aspects.

I'm an economist by training. You can line up 100 economists and never reach a conclusion. So you won't find me -- I think you may be right. Whether we have the statistical evidence to say that's actually true is still in question. It's 12:00? 12:30. We're supposed to break. Is everybody hungry? I don't know about the online people. You probably haven't been waiting. We're going to break for lunch. We'll hear from the statistical agencies after. Thank you.

[Lunch break]

>> Going forward, you will not see much of a departure from what we've done in the past in terms of work and research portfolio. As I said a minute ago, our long-range plan calls for a relative balance across our domain areas. We are sticking fairly close to that. Our portfolio has managed to remain fairly stable and consistent in terms of our investments. You don't see that changing a whole lot.

It's been a long time coming, but we anticipate the stand-up of our disability Rehabilitation Research Advisory Council that's in the incoming months. We put out a call for nominations and have a wonderful group of people we're trying to get onboard. We're also keeping an eye out for additional call for nominations in the coming weeks and months in fairly short order here.

We're excited about that. That's going to be a new mechanism for us to really draw input from the community and get some assistance, input around the work we do.

I guess takeaways, NIDILRR remains steadfast in executing our mission. The mission hasn't changed. ACL is superior, strong organization and we're excited about the opportunities that we have now to learn from, to model for and to grow with our new colleagues over at ACL.

We've got fantastic and knowledgeable folks, peers and real partners, both in ACL and in the broader HHS context. So while we're doing all of this, we're still continuing to engage and try to be as responsive as we possibly can to.

I certainly congratulate the team on the publication of this year's compendium, and it's again a tremendous piece of work. Congrats, and I will stop here.

>> Andrew Houtenville: Great. Thank you. Thank you, Kristi.

>> Kristi Hill: Sure.

>> Andrew Houtenville: If you're not familiar with NIDILRR, it's really a very small organization that gets a lot of things done and has a big scope of work. The population with disabilities is quite diverse, and they try to touch on health, health and function, independent living and community living, employment, technology, and then also statistics and demographics with us.

So they've been pretty consistent over the years with their focus and they try to spread out the love as much as they can with the various topics, and it's really a nice, dedicated group of folks.

If you ever have the opportunity to do grant review for them, you will get to know some of the staff members very well, and it's a really great opportunity.

I think for folks in the research field doing reviews is one way of getting kind of infused into NIDILRR's approach and NIDRR's mission.

For folks who are advocates, one way with this new advisory council is really a great connection that folks can make with NIDILRR and we look forward to that as both grantees but also as kind of advocates. We appreciate the work that NIDRR does.

If you ever had grant funding, NIDRR, NIDILRR, is probably the easiest grant organization to work with, because they've really done over the years a great job at winnowing down reporting to the bear necessity of what they need to report. They don't collect things that sit in a file somewhere and gets moved along. It's a great organization to work with, and we're glad you survived the move from ACL.

>> Kristi Hill: Absolutely.

>> Andrew Houtenville: I'd say everybody clap, but you guys all look fried from lunch.

We're going to move to the next panel. This is all one big panel about agencies. One other thing NIDILRR, being a cross disability, but especially now with ACL, it's really disability spans all of the agencies, and the folks here are from -- two from CDC, one about BLS, one from sen us. They're all related. One in Hyattsville, one in Atlanta. We have the best people to talk to about what's going on with the collection of disability statistics and where the agencies see the future going. That's what they've been asked to talk about.

Our first speaker is brain Brian from the National Center on Birth Defects and Developmental Disabilities at CDC in Atlanta. Amy Steinweg from census after that. Julie Weeks from National Center for Health Statistics in Hyattsville. Then Renee Marshall from Bureau of Labor Statistics. I'll turn it over to Brian first. We'll probably ask people to come to the podium and we'll try to work -- each presenter has about 11-12 minutes. As you saw, people really like to ask questions and I love answering them. Let's try to keep this tight and fast and we'll let a lot of questions come.

>> Brian Armour: Thank you, Andrew. I appreciate you inviting me. I think this is year five or six for me. This guy knows more, I guess here forgotten more about disability than I will ever know.

>> Andrew Houtenville: Thank you, Brian.

>> Brian Armour: He's been a great friend and mentor.

>> Andrew Houtenville: Mentor?

>> Brian Armour: Yeah, yeah. More than you know.

[Laughter]

But I may go a little rogue here.

[Laughter]

Uh-oh. I used to think when I first presented here, I would talk about the differences for people with disabilities compared to those without. That just got me frustrated over time. I think it was echoed certainly by the gentleman here from Department of Defense and others this morning, that I could come here year after year and show little improvement. More recently I was asked to think about how can we make a difference. That's consumed me. I'm pretty passionate about it. But it's very frustrating.

So today I'm going to talk about what the first steps are or how some of us are thinking perhaps how to make a difference. I really 12 minutes is not enough to talk about this. I'll rush through it. I apologize for that in advance. Here we go.

I'm Brian from CDC. Unlike Andrew, I'm an economist, but unlike Andrew I think work is a four-letter word. I know work is a four-letter word.

This is joint work with folks from Delaware, Massachusetts, New York, South Carolina. At the end of this hopefully you have a better idea what we're trying to do in IDD. I'm drilling down, as opposed to talking about general disability. I started with paralysis, spina bifida and people with limb loss. I'll talk today about IDD. This is what we call health surveillance work. That is not a dirty word.

What do we know about people with ID and DD at a state level? Next to nothing, I argue. I hope Julie doesn't disagree with me. She might. What we have is necessary, this is my frustration, this is what I did. I wrote papers, I talked about all these differences. It's just not good enough. It's necessary, but not sufficient. We have these public health information sources, national surveys and disability measures are collected. BRFSS moved to five of the six ACS questions. It will be in there. Yeah.

>> Andrew Houtenville: Advocacy works.

>> Brian Armour: Thank you, Lewis. What can we do with these surveys? We can tell you there are lots of problems. People with disabilities are obese, inactive, they smoke, they don't get mammograms, they have hypertension. It's a lot worse compared to people without disabilities. That's what I used to do. I published a lot in this.

But the problem with that is the case definitions of disability are not intuitive. When I go to people in CDC, I ask them to think about mobile limitations. They look at me with stares.

If I talk about cognition, it's even worse. We think it may lead to depression. We don't know what these groups we like to stick disability into. Some are intuitive, like low vision and difficulty hearing or deaf. Those are intuitive. Many are not. Those are -- the groups that are not intuitive are usually the bigger groups.

We have 18 state programs. We spend millions of dollars on these programs. When we're asked to give time for them, it's really difficult to show how you made a difference. A few years back I was asked, hey, how can we show with these programs? Can you integrate them with other programs, like Special Olympics and The Arc? That's what I've been thinking about.

I came back to the person who asked me, it was around Christmas at the time, I said Gloria, even Santa has a list. He knows who is naughty or nice. We need a list. We need a defined population that we can get back to.

We first need a defined population. I suggested folks on Medicaid, why each state has a program. I can define value. I think of it as intersection of cost and quality. We'll get to that later.

We look at dollars spent, which is important. Many people on Medicaid or disproportionately poor and a number have IDD. Again, I think we need to show we can get back to those populations.

Unlike those national surveys, BRFSS, I think ACS, we can't get back to those folks. We can talk about their issues, but I don't think we address them well. Again, my opinion.

I'm an economist, if you follow the money, it's a no-brainer. We'll focus in on New York. Medicaid population, 5.5 million, 2010. Disability population, 790,000, about 14%. Expenditures, 2010, 42 billion in New York. 14% of the population accounts for 47% of the expenditures. It's the same in every state that you look at. About 1 in 6, 4 in 10 or sometimes half of the expenditures. We should want to know more about what disability means.

What I did, I started with a pilot project. I've learned a lot working at the CDC. Don't shoot for the moon. Get something that works, expand from there.

We started in South Carolina, identified Medicaid beneficiaries with IDD. Not only IDD, again, I imagine folks are going what does that mean? We looked at subgroups, Down Syndrome, CP, autism, etc. We looked at demographics, healthcare use, hospitalization, patient visits.

Quality of care, I looked at ACSCs. Which I'll talk about very briefly shortly. Also total expenditures.

We used ICD-9 codes. This is how docs get paired, based on conditions. We defined, Andrea and I had this conversation earlier, the same patient, service provider and dying noise.

We used this Medicare disability algorithm including individuals with one patient or two other service encounters with diagnosis code. And 11-12 months of eligibility. The reason we picked that, I want to look at expenditures over a year.

Here are the codes. These are Medicare codes. I reached out to Special Olympics and The Arc. I asked them to kind of confirm these, change them, whatever they wanted with them. They were pretty happy with them.

These are different groups, mild, moderate to severe, unspecified. Specific conditions, CP, etc. Decided right off the bat that we needed to make she's mutually exclusive so folks could show up in two buckets. You could have Down Syndrome and moderate to refined ID. Where there was a specific condition syndrome, we put you in that bucket. Where there was none, you are mild, moderate to profound or unspecified. The reason we did that, we didn't want to have a number in the subtotals bigger than the total number, basically.

In South Carolina this is what the population looked like over the period 2001-11. We identified about 70,000 people with IDD. About half, a little more than half, were 0-18 years. 62% were male. Most -- not most, majority were African-American, 45%.

Good news, the line here to look at is average length of time in years. That says 7 1/2 years. You get into this program, if you have IDD you typically stay in that program. Again, if we want to make a difference in their health it's important we can find them again. Most of the time we can find them again.

When we looked at their utilization, this is what they were hospitalized for. Diagnosis, it was epilepsy. Anybody here that is familiar with the IDD population, that's not surprising, about 35% have epilepsy. Other things that showed up are UTIs, pneumonia, which shows up in all states. Though I'm not presenting that today. Also dehydration, which we think is related to stomach flu.

When we look at all diagnosis, a different picture emerges. Chronic diseases show up when we look at all diagnoses. Again, it's hypertension, and diabetes, and also skin ulcers as well. We also did this on the ED side as well as outpatient. I'm just showing inpatient.

The markers of quality, ACSC conditions, I was handed the holy grail task. What I was thinking about this, I was told think how to improve the quality and save Medicaid money. Hard task, but I think this is the way to do it. ACSCs are conditions like diabetes, UTIs. If you get good outpatient ambulatory care, reducing need for hospitalization, what we find in South Carolina, when we looked over all 2011, the rate for Medicaid was about 16%, so 1 in 6. You looked at IDD, 1 in 4. 1 in 4 hospitalized in 2011 for case sensitive condition. This suggests some value placed here.

If you look at the dollars overall, we're talking a lot of money. We're talking 76 million over roughly this 10-year period. If you look at the total cost of inpatient, it's about 50 million. So we have 50,000 people here with IDD hospitalized for ACSC condition, 81,000 times over this period. South Carolina spent on the inpatient side hospitalizations $50 million. If you cut that, remember, these are conditions if you get good ambulatory care should reduce need for hospitalization. If you are able to cut that in half, you save tens of millions of dollars. This is one state, South Carolina.

We expanded to five other states. We used this community of practice approach, peer-to-peer learning, brainstorming, troubleshooting. This is ongoing work. Showing you New York data looking at

the period 2008-13. Look at the numbers in New York, 162,000 with IDD. Guess what, New York, most are adults. If you look here about 8600 -- five minutes. Good.

>> Andrew Houtenville: A little less than that.

>> Brian Armour: Like 5% are 65 years of age or older. We were able to in New York to break it up into five-year age blocks. So even though under 18 are the largest percentages in terms of those five-year grids, 15, 10, overall they represent about 40-something percent of the New York IDD group. So New York was like any other state. We think we know why, but I'm not comfortable sharing that with you right now. We're still mulling it over.

Another thing that surprised New York, look at race here. 50% with IDD are white. They said our Medicaid population does not look like that. So it was a surprise.

The male is no surprise, particularly when you think of autism, which is one of the subgroups we can look at. But I want you to turn your attention to time enrolled in Medicaid. Over the six-year period, five years, so again, the important point here is when you get them in there you can go back and find them again. If you see the women 40 or older with IDD aren't getting mammograms, guess what, if you go back, you can find those women that aren't getting mammograms and hopefully work with New York and providers to get them mammograms. That's the important point to take away.

I split up items into various subgroups. I'm showing you mild, moderate, profound, unspecified. The numbers in the tens of thousands for most of these groups.

I guess some interesting things to me, unspecified ID, 15% are 65 years of age or older. That stood out to me. Different things stand out with different groups.

Again, average length of time in years from the mild and rad mat profound ID, 5.4 years.

The only people in there that aren't in the whole six years are the 0-4 years old who aren't old enough to be in the whole six years. I hope you kind of get where I'm going with this.

This is some of the expenditure data. Basically people with outpatient visits or IDD there's about 61,000 visits in 2008, 75,000 by 2013. So it grew approximately 25%. Over that time expenditures and ED increased 50% from 22 million to 33 million. That's interesting. What's going on there?

So bottom line, this work is kind of helping us tell decisionmakers and providers who to action on. Don't say approve health and wellness for people with disabilities. Say improve health and wellness for people with Down Syndrome or CP, autism, etc.

We can make a value play here. We can show that by doing this there's a potential to save some money. I think that's the most important thing. One of the most important things, particularly for the programs that we want to kind of focus on these folks.

Increasing our understanding of IDD subpopulations. I certainly don't know best. At CDC sometimes we like to pretend we know best. I don't when it comes to IDD. I need others -- we will need others to weigh in on this. We've already got two papers in the works from this, which is part of our currency.

That's my contact information. Unfortunately, this is work ongoing. I got permission from these two states to kind of share what I have today. Since it's ongoing and the states still need formal clearance processes it's not available in everything that you have.

Thank you for your time.

>> Andrew Houtenville: Thank you, Brian. We don't do clapping around here, but we could have. That's very different data than what you've seen in the compendium and others. It's a different approach. It's using claims data and trying to identify specific individuals with very specific actionable items. I think of reduction of unnecessary hospitalizations, unnecessary ER visits. I'm thinking also people's quality of life. I spent a lot of time going in and out of ERs and doctors. I'd rather not. You'd rather have good care from the beginning as a base.

We're going to jump to almost the opposite sense of the data spectrum to population-based statistics from Census Bureau with Amy.

>> Amy Steinweg: Hi. I'm Amy Steinweg. Once again, with the US Census Bureau. My talk is different from Brian. I have data on what we can offer you.

So I'll give an overview of the three surveys. We have some involvement with that have disability data. The American Community Survey. I feel like you've given maybe half of my talk already. 3 minutes.

>> Andrew Houtenville: That's all you need?

>> Amy Steinweg: Don't overdo it.

[Laughter]

I'll tell stories at the end.

>> Andrew Houtenville: Sure, sure.

>> Amy Steinweg: The American Community Survey, ACS, is our very large survey. It's in a long form. We have six disability questions we began asking in 2008 which is really quite a lot of what goes into the compendium and what you've seen today. They've given my talk.

The Survey of Income and Program Participation is very different. It is a longitudinal survey. As such, a much smaller sample size. But richer data. The ACS is sort of confined, people fill it out. We want to keep it quite parsimonious.

There is a survey with the Bureau of Labor Statistics.

We've been very production heavy lately. We have a little research going on. We have one person looking at small area disability estimates, some modeling of that. Another person looking how we can maybe understand ACS, capture a little better looking at the set data.

Once again, these six questions. This is what it looks like when we ask it. That you saw graphically presented as results.

Very briefly, difficulty hearing, difficulty seeing, cognitive difficulty, the concentrating, remembering, making decisions, ambulatory, walking, climbing stairs, difficulty dressing or bathing which we call self-care, and independent living, ability to do errands on your own.

I'm ignoring my notes. These are slightly different age universes. When talking about the 5 and under on all of these things, the numbers are very small, but I'm thinking you have two questions, right, we have hearing and seeing. So I kind of hope it's small, but you kind of wonder what else is there. It's very different age category.

Just to mention regarding these questions, in recent years the Census Bureau has had evaluated questions on the ACS. Not just disability. To ensure we can justify that the benefit warranted the cost. When I say cost, I'm not so much talking dollar signs as really respondent burden. It's a very large sample. There's a lot of people that we are tracking down repeatedly asking them all of these questions. We needed to justify it was really necessary, each and every one.

What they did, they looked at two vectors. They looked at cost and benefit. The cost again respondent burden, does it annoy them, is it too invasive? They had a grid, high, low. High benefit, low cost.

Disability as it happens is a bit high cost, and that it's a little bit personal. Right? We've already knocked on your door three times. You let us in, we want to know all these things. We ask whether you can dress yourself, bathe yourself. It seems a little weird, right? When you're not one of us who knows why we're trying to measure these things.

OK, let's look at the benefit. Of course, we need this data. It took us tapping all the different agencies and forcing them to write what are all the things you do with this data? What are all the things you have to do? You have no alternative data sources. It was a lot of work.

Of course, we get to keep it. We're happy. To point out there's a lot of data we'd like to have. Myself included. Unfortunately, sometimes we have to keep working to keep the data we have. This is the environment that we're working in.

The ACS again is our largest survey. 2014 we conducted interviews from over 2 million households and over 165,000 persons living in group quarters. We can produce estimates at very low levels of geography. The one-year data goes to population 65,000 or greater. Five-year data, we can go almost everywhere else, counties, places and census tracks. It's widely used, local governments, counties, private planning.

Then I talked a lot about the American Fact Finder already. This has been sort of the key place looking at the slides instead of you, I'm sorry, so where do you go to really readily find our data? American Fact Finder, AFF, through the census website. We have lots of tables. It's really nice you can pick your particular area, then pull up a table, it's just about your area.

We have several dozen devoted just to disability. We've tried to figure out how we should tabulate it. It's come up a lot over the time though, we kind of want to cut a different way. We'd like to see something a little different. If there's anything that I can lobby for we're most likely to get, it's probably a different table.

Let us know. I'll pass it on. The data users want to see this thing, let's get to the times. Certainly give me feedback. My contact information is there. If you want to ask questions, we'll go up higher.

[Laughter]

The one-year release for 2014 came out this past fall, September 2015. Latest five-year bundle 2010-14 came out in December. We talked about how to go very low with the five years.

If you want to make comparisons with the five years, you're not supposed to look at overlapping samples. We don't have two five-year samples yet. In a couple years that may be something exciting. One new thing we have that launched recently using ACS is called the census business builder. As the name suggests, it is largely targeted at business folks, people wanting to start a business, grow a business. But I think it has some real utility that folks in this community can use when doing different aspects on disability.

So what's different about this then than AFF? You're looking at ACS, aggregating statistics, looking by geography. It's a lot in common. We're bringing in economic data, economic census a few different places pulling from. When you plug in your geography now, you get new numbers. There's things that I think could be useful. You go into an area, you see the disability rate. You can pull up a number of businesses in certain industries. So it will pull up for you the number of doctors' offices in that area. Do you have enough doctors' offices given the disability rate? Is there an issue there?

Home healthcare, taxi services is the only thing I saw so far in terms of mobility.

Then also employment by business type. Maybe super high disability rates but only blue-collar, intense physical stuff. Maybe that's something someone is interested in who's running the number for me.

So this is really launched, and there's a couple different versions. 2 minutes? I don't get to tell stories at the end.

>> Andrew Houtenville: You can do it in Q&A.

>> Amy Steinweg: Not to offer for them, but I suspect in feedback came to us saying you include this industry, we really want to see this one, I think they're kind of interested in hearing feedback how people can use this and really it's all about making our data work for people. We put a lot of work into collecting it. We want them used as widely as possible.

Then it makes maps. Everyone loves maps. I pull this up. Washington, DC in the middle. Disability rate, 11.1%, then I pulled out so you can see community variations. It does that too.

On the SIPP, Survey of Income and Program Participation, we talked about this as well. Table 2014. We're trying to be more cost efficient in data collection. There are implications for that. One good thing is we're now collecting more data on disability every year. So every year -- before it was disability, now we have the six set of ACS questions. For children under 5 we talked about that under 5, there is a developmental delay question that I think is going to be really interesting.

Two questions for kids 5-14 about kids-type stuff. Playing with other children, limitations in schoolwork. We have I believe three employment questions, so the classic limitations and amount or kind of work you can do. But trouble finding or keeping job.

This data is huge, redesigning is huge. Processing is huge. We do anticipate it in summer of 2016. We've been working real hard on it. We hope to see that soon.

All right. So in the redesign we had these topical modules, we'd go out three times a year, tack on a topical module. Now we go once a year, we stay a long time in your living room. We're not going to stay for dinner. Doesn't work so well. That was a lot of our really good disability data. Happily we have an SSA supplement funded by Social Security. It combines most of the content from our work disability, adult disability, child disability topical modules and other stuff. That's important too. But of course, what it is is you participate in wave 1, we follow up with you. It is a phone survey. We're currently processing that as well. We've already collected that.

We need to put out wave 1, then follow up in the fall with that data.

CPS basic, again, this is largely BLS territory. We're interested in using it for our health insurance poverty income reports. It allows us to do that.

A little bit of research going on as I said. We have a guy, Jerry maples, doing ongoing work to see if he can model small area estimates of disability, sort of ACS geography with SIPP richness using different modeling things.

Any information you want on that, go through me, I will connect you to him.

Then a newer research in our branch doing a lot of disability work, Danielle Kayler, looking across ACS and SIPP to see who is in the core group of six-question people we've put so much weight on. That's new, but it will be really interesting.

Some links. My contact. I'm Amy Steinweg. You can call me directly, 301-763-3834. Amy-point Steinweg@census.gov. Any help you need, we're happy to accommodate. Thank you. That was the fastest presentation I've ever given. I moved along thinking I had a lot of time.

>> Andrew Houtenville: Thank you. Julie Weeks from National Center for Health Statistics.

>> Julie Weeks: Good afternoon. The Centers for Disease Control has lots of centers. Most of them are in Atlanta, and Brian is in Atlanta. The center I work for, the National Center for Health Statistics, is here in Maryland. It also serves as a national health statistics office for the federal government. I mention that up front because, I will touch on that in a minute.

The other thing I was resonating with earlier today, this intersection of aging and disability, the branch that I run, the three major topics are injury, aging and disability. Our researchers collaborate greatly across those topics.

Today, when I was thinking, OK, what's been the update since last time I spoke here in 2011, I wanted to mention a couple of things that are unique to the ACS questions. Maybe a couple reminders.

I wanted to talk about the sets of questions that had been developed and are now the international standard that are going on to NCHS surveys. Then I want to talk about the national health interview survey redesign. Many of us use the HIS as a source for our disability research. Now is the time to get involved and voice your opinion to the content.

There's very little to say about the ACS here that hasn't already been said. But I did want to mention as an opportunity for people using data to think about, at the very bottom, the second bullet, the ACS set has been adopted as the federal standard and is now being collected across quite a number of agencies. In fact, Justice has it on the crime victimization surveys. Pardon?

>> Andrew Houtenville: They finally did it.

>> Julie Weeks: Their standard reporting now has all of their crime statistics are disaggregated by disability. So those are some, actually -- it's very positive news.

The other thing about that, at NCHS we link Haynes, our examination survey, and HIS, which is our population-based questionnaire survey, with data from other agencies. So for example, our latest linkage has Haynes and HIS data linked to HUD data so you can start to look at, by disability, issues related to housing and health. And without those linkages you can't look at those three together.

I'm not going to go through this because we've covered a lot of this already today. But the ACS now, again, has been -- you see it all over the place in terms of federal reporting. Our standard reports now include disability finally as a disaggregate as a demographic, and that's exactly what we had hoped for.

You know what the ACS questions are. I want to pause here for a minute to remind everyone that when the disability questions were being redesigned for the census OMB put together an interagency group, which NCHS headed to really look at what questions need to be on this. There was a large amount of work done, including quite a bit of testing. There were some questions earlier today about how the respondents answer these questions. A few other kind of administrative issues had popped up.

There's a very comprehensive testing document available on the web, by Matt Brault. A lot of those issues in terms of using these questions are on that.

I also want to remind people that when you look at the question wording for these six questions, because of the size of the amount of real estate, the space on the questionnaire, the response category had to be yes/no.

If you're going to ask somebody about their ability or their difficulty to hear and your only answer is yes/no, the decision was not to cast a wide net, but to cast a conservative net, one that people felt more comfortable with.

So when you look through the questions you will see serious difficulty hearing, serious difficulty seeing.

And when those words were added, you saw a lot of the measurement issues go down.

Keep in mind, this isn't just difficulty hearing; this is serious difficulty hearing. So you have confidence that you have some people who might experience participation restrictions from that.

I want to move on to the Washington group questions. The work of the Washington group has been going on over 10 years now. Again, it is centered at NCHS. The point of this is to create a standard set for international use. So we have a federal set of questions. Now there's international standard.

Here's one of the issues -- or one of the goals when we developed this set. Besides the fact that the questions had to be cross-culturally comparable, so if I can ask you a question in Costa Rica and ask you a question in Greece and Oman, it has to mean the same.

So we've tested in all regions of the world. But one of the things that we wanted to do was to create a set of disability questions that weren't simply yes/no.

We want a continuum. There are people with gradations of severity, and it's really important. So you will see when I show you the Washington group short set of six questions that the response categories are expanded.

I have handouts. This will be on the web. This is the background for the Washington group meeting. I just want to call your attention to the fact that every national statistical office, over 133 countries, have been involved in developing these, as well as NGOs, disabled people's organizations, ILO and others. We end up having meetings in different countries every year, but we also have tested in every region of the world.

So I think as much work that was invested in the ACS set, there's an equal amount of work invested in the Washington group set.

The Washington group has developed a short set on function. That's six questions. It's been adopted and enforced by the UN and now on censuses.

There's an extended set on functioning. That was adopted in 2010. It adds not only questions within domains of functions, so you get more questions on mobility, but it also adds other domains of functioning, such as affect, pain, fatigue, upper body, which you don't get on the six questions.

With UNICEF there's a module on child functioning and disability. That is being released this spring. Testing has been completed, and now development, a module on inclusive education.

All of this, not the child stuff, all of it is on the HIS now, and has been.

So the short set is very similar to the ACS question set. Not terribly different. We have a communication question, but you will see that there is now a range of response set from no difficulty, yes, some, yes, a lot, and cannot do at all. So the extended set has the additional questions in hearing, cognition and mobility.

The additional functional domains that those additional questions ask about is upper body, anxiety, depression, pain and fatigue.

So let me move on to the HIS. The last time the HIS was redesigned was 1997 as an extremely large household population survey and gives us most of our additional national statistics on health.

It's been in the field since 1957. What has -- the uses for the data are contributing to the very reason we really are at the crux of needing to redesign. The question is very long, response rates have been trickling down. So about 100 minutes. So many people need the data from the HIS. It has a large number of uses.

Here's the amount of disability or functioning content on the current HIS. Many of you, if you are data people, have used these questions over the years. But when you look across these topics these aren't single questions, they are batteries of questions. So the HIS really in no other area outside of function is dealing with a huge amount of overlap and at this point they're really questioning do we need these questions? What are the programmatic needs? What are the research needs? Something is going to go.

In fact, a lot of it is going to go.

There's a core, the format of the HIS has a core, then durable supplements that will be paid. I can say with some confidence that there will be supplements that are paid in the future, but I do not know that the core, as most of us are used to using it, will stay the same. Especially family questions.

Yeah. Thank you. Whoever did that.

[Laughter]

So what happens, and my final slide, I'll put the 2014 in here, but this is how complicated the questionnaire for the HIS is now. And so thanks for that "whoa."

Here are the goals of the redesign. Obviously, it's to shorten the questionnaire and improve the flow and keep only the very things we really need to keep.

Here's the timeline. We find ourselves in 2016. The people in charge of making the final decisions are really receptive and receiving any information from any source that wants to provide it, and in a slide or two here I will show you where you can provide your feedback.

The one thing we are required to administer the ACS questions. But there's no requirement to ask them each year. That is right.

So what is likely to happen in terms of the format of the HIS is that there will be a much smaller core. It's going to be 15 minutes only, that will be asked every year. But then there will be another section that rotates on. So in a year you might get these questions, in B year you get these, in A year and B year. If you are shaking your head as an analyst, knowing that you what you want will invariably in the opposite year your outcome is.

So pay attention to this last slide.

I don't get to make these decisions, I just happen to spend all of my time using that data. So I'm writing secret e-mails, getting advocates to send e-mails, as much as I can.

>> Andrew Houtenville: You know we're broadcasting?

>> Julie Weeks: I don't care. I say this at the office too.

There has been a Federal Register notice. There will be another one this spring. There are places on the NCHS website where you can provide your input. Here are the things that the folks in that division need to know.

>> Andrew Houtenville: These won't be available.

>> Julie Weeks: Yes, they are. And I am done.

>> Andrew Houtenville: Thank you. That's good information. As I mentioned, advocacy is a big part of maintaining disability statistics and getting the questions answered that you have.

Next we'll hear from the Bureau of Labor Statistics and Renee Marshall. Renee and I have never met. Hello.

>> Renee Marshall: Pleased to meet you.

>> Andrew Houtenville: For years we had the benefit of working with Terry McMenamin who passed away a few years ago. Renee will ably take his mantra.

>> Renee Marshall: As mentioned, to keep us moving on while getting to that, I'm Renee Marshall, I'm supervisor economist at the Bureau of Labor Statistics. I'm here, I'm going to talk today about the occupational requirement survey. It's a new survey we have at the Bureau of Labor Statistics, and we love our acronyms. I will try to use as few as possible in my presentation.

The occupational requirement survey we refer to as ORS. Will see that on the slide. It will likely slip into my presentation, especially if I'm trying to keep on time. It's always shorter to say the acronym.

My first question I want to answer for all of you is what is the occupational requirement survey? What it is is a new Bureau of Labor Statistics survey. It's designed to produce occupational requirement estimates that are similar to what were published in the dictionary of occupational titles. It is not a replacement. We're not trying to replicate and update the Dictionary of Occupational Titles. It's similar but different. It is collected, the survey is, from employers by an interview, maybe phone. A lot of it by personal visit. It's not a mail survey. Not filled out by workers, employees or individuals, other than the employer representatives.

And it is funded by the Social Security Administration but collected by the Bureau of Labor Statistics. So I know you're familiar with at least the basics of the Social Security Disability adjudication process. I'm not going to get into any of that, other than that as you know, they have used as part of their adjudication the Dictionary of Occupational Titles, which was an output from the Department of Labor from 1938 until the mid 90s. In the 90s, the Department of Labor stopped jut dating the Dictionary of Occupational Titles.

What's happened is that over time, SSA has had an issue with that last revision becoming out of date. The economy has shifted from a manufacturing economy, away from that heavy manufacturing,

which was a lot of the jobs represented in the DOT, and also technology has taken over the workplace and it's really changed how things are done.

If you look at the last published occupational titles the only reference to net in there is the manufacturing of fishing nets. That gives you kind of an idea how in the last 25 years technology has really emerged into our workplace.

So that's been an issue for them. They've been looking they recognized this many years ago, started looking at a policy group to look into the issue, I'm not going to cover all of that background. It's available on the SSA website. If you're interested in it.

But a couple years ago, what they came down to were they were looking at several options. They could develop their own product. They could use an existing product. The existing products they looked at Department of Labor or the O*Net, which was kind of the replacement for where the Dictionary of Occupational Titles moved. It's its own product, but that's its child.

Then the Occupational Employment Statistics program. And the national compensation program. None of these existing products really fit in with SSA's needs. They did find there were several aspects of the national compensation program platform that really fit in with what they were looking for and were desiring in the survey.

Some of those high points are the survey management. It was direct contact with employers. It wasn't going out through workers. It was asking what is it that you as an employer are looking for and expecting as the physical demands, etc., national compensation looks at work levels.

It was asking the employers what are your expectations? What are your requirements? It was looking at professional staff doing the data collection. So it's not a mail survey. Someone is there who understands the concepts behind the questions and is able to answer details whether something would or would not fit in.

The national compensation program collected information on the levels of work. So it asked about knowledge required for doing the job, the tasks that are there, the physical demands and contacts that the occupation would have, all for determining a level of work.

Also that data is all collected and coded by occupation. So these were things SSA thought were good fits for what they were trying to do, then that entered into some discussions with the Bureau of Labor Statistics to come up with an agreement that we emptied into in 2013 for developing what has turned into the occupational requirement survey.

Here we are in 2016, three years later, and we are at our first year of production collection. There are several items that you will find are familiar from the DOT, though they are not directly related, but the other fourth bullet in my next slide is grayed out, a new area not found in the DOT. This is all based offer SSA's requirements for what information they need as input into their disability process.

So the Occupational Requirements Survey has three main areas we're capturing. There are, I believe, 70 data elements that fall underneath. This I will not list all of them. You can find them on our website, which I will share in a minute.

We are looking at physical demands, environmental conditions and vocational preparation, all areas that should be very familiar from the DOT.

To give an illustration, on the slide there is two men standing in the woods with a piece of survey equipment in front of them. We'd be talking to the occupation -- or talking to the HR official, human resources official, about this occupation, saying, OK, so tell me about this job. They would be telling us, well, it requires work outdoors, and they are required to stand, and I bet they had to walk to get to here, so that involved walking. Someone carried that equipment. So they may be telling us they had to lift and carry equipment to get there.

They're obviously looking through the piece of equipment, so there's some level of vision that's required. Collecting that type of information.

Also asking what type of preparation do they need. What type of training or previous experience. They have to be able to take these measurements and record them. So what are the requirements for that to perform the basic functions of this job.

So those are very similar to what information is available from the DOT, but it's been refined, captured and some information from the DOT we're not capturing, some are refinements that are new.

The other speakers all spoke about the fact that we have to balance the amount of data everyone would like to have with the amount of data we're asking people to voluntarily provide. So it's that balance.

The new area is cognitive demands. This is something that I've seen mentioned. It's an area that SSA has recognized is a growing piece of their disability adjudication process and there isn't data there. So there are some new data questions that we've added. That's going to provide some information just to give you an example what's in there, contacts, how frequent does the job have contacts with other individuals that requires some personal interaction? What are the frequency of changes to work location or work schedule? An idea of information underneath there.

Outputs. It's the first year of production, so I don't have anything to put up here to show you. We are in collection through August, then will have time required for analyzing, processing, getting everything through our estimation and validation process.

So we are expecting to have a release at the end of 2016.

Our goals, what we are trying to do with the outputs, identifying what the users need. As we're going through, prioritizing, putting out the information that is most useful, making it easily understandable. We love our tables because that's an easy way to put out data, but not really the easiest way for all users to understand the data. So we're looking at different options for being able to present the information. We want to make sure that we're publishing estimates that are useful. Everybody always wants the finest level of detail. Especially for occupations. So we're using the same occupational classification coding as the O*Net. All federal statistical agencies are required to use the standard occupational classification system. The O*Net adds a level of detail, with additional two-digit breakout for select occupations. That's the level we're coding at and will publish at when we're able to.

I mentioned that we don't have anything to share on our actual estimates. There is an article published in the monthly Bureau of Labor Statistics monthly labor review, in November 2015. It's the Occupational Requirements Survey. Let's see, the exact title is Occupational Requirements Survey estimates from preproduction capacity. There's a big link at the top of our website.

One of the things also is who else might use the estimates. We don't really know. We haven't published it. There are people and groups that reached out to us. We have our own environmental scanning. We're thinking this data may be of interest to the Department of Veterans Affairs, education, disability insurers, workers' comp, vocational experts and others. A new data set. We'll see where the data users come from.

BLS is continuing to work with SSA. All of our survey, they're not static like the DOT is now. They are ongoing development. As the mix of the economy changes, we should be reflecting that as our survey publication comes up, we're doing validity testing. We may have some modifications we need just to make sure what we're collecting and putting out is the data that's needed. Some of the other speakers spoke about adding in a word to say serious really can change what kind of data comes through. We'll do that testing to make sure what we're measuring and putting out is of use to the data users.

We'll expand the data available for the disability process hopefully as all of this. What we're getting is something coming in. A very important point, this not the only information, only source of data SSA will use and have in their new occupational information system they're developing. Just a piece. We get lots of questions, what about this other piece? They may have other sources for that information. We're going for what is most important to for this particular survey.

Where to find more information. Www.bls.gov/ors. Right there. That's its own webpage. There's links to all of our developmental information, our forums, procedures, etc. There's a link at the bottom for sending an e-mail, asking questions. You want to have somebody specific respond to a question about it.

Also the TDD information line. That's for any Bureau of Labor Statistics project that you may have had or question that you may have. That number is for everyone, all of the programs.

Every BLS page, if you ever have questions about BLS data, at the bottom there's always a contact us button. You can use that. It will find its way. Again, Renee Marshall. My contact information. Marshall.Renee@bls.gov.

>> Andrew Houtenville: Thank you. That's really a great smattering of resources from this panel. Administrative claims records, detailed health information about NHIS, how it's going to be modified and under revision. The census products which are the core of the base population statistics in the US. Then the occupational requirement survey, which is pretty timely, given that DOT is now older than many of us here, but not me.

It's really important to understand if disability is an environmental characteristic, the requirements of a job will influence disability. It's not people who have disabilities, but people who experience a disability and that disability is health characteristics of the individual and the environment. A work disability, a work-related disability depends on requirements, and matching people to jobs, matching SSA applicants of as applicants come in, and report their medical information, hopefully share functional information, perhaps that can be used to match them to jobs according to requirements that are solicited through something like the ORS.

So questions?

>> Does the ORS differentiate between full-time and part-time?

>> Andrew Houtenville: Does the ORS differentiate between full, part-time, unpaid?

>> Renee Marshall: When we collect the data, we're characterizing full-time vs. part-time. That's how we capture it. In terms of what we're publishing and putting out that has yet to be determined. It will be based --

>> Andrew Houtenville: Yeah. That's a really important question, because what's necessary for a job and what can be split off if it goes part time differs by occupation, maybe firm-by-firm, industry to industry.

>> Hi, I have a couple of questions for Amy. One is I noted in some of the -- I think this was from ACS data, maybe not. You have information on Puerto Rico.

>> Andrew Houtenville: That would be ACS.

>> I'm wondering if there is any talk about including information from the other four US territories and census data going forward, then related to that I'm wondering do you have a feel for how representative the data collected is of those in Indian territory? On reservations. Because of the way it is collected I imagine it would be difficult.

>> Amy Steinweg: The latter question first. I don't know a lot about that. We had an analyst here years ago that did some work with Native American population. Honestly, I'll get back to you. The island area stuff, we do so much, right? Small slices. There's island area stuff going on I don't know

the details of. Do you want to e-mail me? Give me your card, I'll get back to you.

>> Thanks.

>> Andrew Houtenville: OK. How is online? Any online questions?

>> No, we're all set.

>> Andrew Houtenville: Nothing yet?

>> Nothing yet. I will ask if they have any questions.

>> I do. Hello. Rebecca with the American Foundation for the Blind. I wanted to again commend the Census Bureau and National Center for Health Statistics for every time I go to the webpage there's a new way you are making data available. I wanted to encourage everybody to try tools like beta ferret. Every week there's a new webinar and training. When we as a community learn and have people in our organizations who can access this data, then we are even more empowered by the data and the questions that we're particularly interested in.

I wanted to thank you all and our government for making these sites more consumer friendly, for getting data. Accessibility, of course, for those users using screen readers.

Then a specific question. There is a difference, and I don't know about all six disability questions, but between the question about vision loss on the national health interview survey and question about vision loss on the American Community Survey. It's like a three-word difference that has like an enormous variation in the result. I wonder if you thought with the revision of health interview survey should we be thinking it's going to look more like the American Community Survey question or is it going to stay the same?

>> Julie Weeks: There are lots of questions on vision on the HIS. So I would be surprised if the ACS vision question that's on the health interview survey varies in wording from the ACS question. Because it shouldn't. It wasn't designed that way. They are supposed to be a set and we are mandated to administer them the same way.

Having said that, on the sample adult, on the sample child, the family questionnaire, the core and several of the supplements we have other vision questions and those could differ in many different ways.

So if you show me the specific question I would be able to answer why there's a difference.

>> Andrew Houtenville: Yeah, there's also differences that it might not just be the wording. The mode it's asked in. Eric and I are doing a lot of work across all the data sources that asks the six questions. We get for each question, division question, a lot of differences. So it could be just the mode, not necessarily just the slight wording.

Like the CPS, there's a lead-in question that says we're going to ask you about activity limitations. Automatically it's framing people to a more focused, trying to reframe people towards activity limitation. That may influence certainly vision question, which is the next one in line. Question?

>> This is Phoebe Ball with the National Council on Disability. Legislative affairs specialist. I had two questions. One for Renee, the other Brian.

Renee, I wanted to ask you about the Occupational Requirements Survey. Are there any questions related to where the work has to take place? I'm thinking of the jobs in the economy that you can work from home, telework, that kind of thing. Is that reflected?

>> Renee Marshall: No.

>> The reason I ask, obviously getting to work, transportation barriers were a big issue for people with disabilities.

Brian, in terms of your work, I'm originally from Iowa, so I keyed on the fact that that was one of the states you were involved with. They've recently had a very difficult rollout of Medicaid managed care.

I wondered, that made me think more broadly, do you know if Medicaid managed care was factored into the work you're doing and how that will impact going forward, especially in Iowa?

>> Brian Armour: Excellent question. Yeah, Medicaid managed care matters. So I guess 20 years ago this would be really problematic, because we wouldn't have had expenditure information. I think Medicaid programs have gotten pretty savvy over time and New York has some Medicaid managed care. We can get estimates from the managed care as well as the fee-for-service plans.

It's funny, Andrea and I were talking a little about this earlier today. What is tricky is when you get into the weeds and you have carve-outs for people with disabilities, and as an economist I'm really interested in the expenditures. That can -- you can try to change a policy and it can benefit one and cost another. Trying to get them all together to figure out what -- it may be the right thing to do, but trying to get everyone to agree on it is really difficult because we get this data after the fact, and these, several years after, these programs change all the time. You can make a financial argument for one that two years later is not there. So you're answering -- it's a really good question. It's really -- we can get the data, but sometimes answering the policy questions are difficult because the program has moved on.

>> Andrew Houtenville: Next question? Dave?

>> I'm David from Mathematica. I will continue the questions to Brian and Renee. Renee, a methodological question for you, which is between your three surveys, the CPS, the ORS and national compensation survey, my question is could you create a statistical linkage to get a comprehensive view of a worker's characteristic, both individual characteristics from the CPS, and then link from the NCS their employer characteristics and the demands from the job from the ORS. Is that something BLS is thinking of? Is that even a valid method? I'm thinking of a comprehensive view of the person at their job.

>> Renee Marshall: I'm going to have to take that question back to someone else in terms of details specifically of ORS and NCS, they're very closely linked. We're using the same samples, sample methodology type information.

So that's a different question than tying it with CPS, which is its own structure and outside of I don't really know any of the details about that. I can take that back. But right now, we're just focused on getting out that first year of ORS production data, then seeing as it all comes through how it can be used.

>> Andrew Houtenville: One thing that might be helpful is you mentioned doing estimates for O*Net, but also for the SOC. Because CPS is still based on SOC codes. So is loosely ACS as well. Being able to have estimates for --

>> Renee Marshall: The O*Net codes are all a subset of SOC codes. The first six digits are SOC, then two digits added on, which are --

>> Andrew Houtenville: I never knew that. I always like turn my nose up at O*Net. That could help answer your question and cross-walking between the type of occupation a person has, the characteristics of those people, then going to ORS.

>> Brian, I have a question for you. I was very compelled by the data you put up on emergency room visits by people with disabilities. I know these are preliminary data and analysis. My question is one of policy, which is what are the states planning to do with the data? Because you could see sort of very clear types of intervention and approaches, such as behavioral nudges, when somebody shows up to the emergency room for the first time, that they get some sort of care coordination to give them advice how to use medical care. Has any of that advanced planning been thought of with the states or is there any sort of coordinated efforts at those levels?

>> Brian Armour: There's no -- they've told me what they don't want to do with the data. They've said they don't want -- we have five states here. Where are we going with this? We're going to look at things like, are you familiar with PQIs, prevention quality indicators?

>> I should be.

[Laughter]

>> Andrew Houtenville: That's a good way of saying no.

>> Brian Armour: You should be getting things like eye exams, foot exams, A 1 C levels. I'm no clinician. But your A 1 C levels should be within a certain range. Those are quality measures. We can link up the expenditures. If you're not getting good quality, you will be hospitalized more, may lead to other heart conditions, etc.

Where we want to go, we want to do this jointly with clinicians, figure out the low hanging fruit in terms of quality measures, things we can address and get the Medicaid programs to address across states that will potentially save them some money. I don't know if it will, but it will definitely improve the quality of care for people with disabilities. That's where we're going.

What we've got to be careful, it's got to be seen as quality improvement, not seen as, I'm making this up, Iowa ranks last and New York is first. We heard that earlier, where someone said you usually think of Alabama and Mississippi as being, not the New England states.

State Medicaid programs will be very sensitive to if feds get in there and start ranking these states. I know they do it on the Medicare side, through their quality improvement programs.

We're just going to have to be very careful, because these states are working. I do not have the funding to do what I'm doing. A lot of this is in kind with a little funding. So where we're going is we're going to try to improve quality of care and do it in such a way that our resource centers, advocacy groups that you would call them, like Special Olympics, can support it and it won't show the states up. It's going to be a tightrope, basically.

>> I think to the extent that you could move states away from this is a ranking, more towards this is a collaboration, if you could throw in some sort of qualitative exercise, once you find the quantitative differences, I think you'd have something extremely powerful. You're looking at very different Medicaid programs. New York has county-based Medicaid program that is very messy.

>> Brian Armour: Our first paper we started to look at Kaiser Family Foundation has publications that show you the different -- you're right, we have apples and oranges with these Medicaid programs. What we have is tremendous opportunity to improve health and wellness for people with disabilities, subgroups, IDD, paralysis. What you're saying really resonates. What we're going to have to do is say state A, state B, state C. As we get this going. If it grows into a 50-state program, which I hope it will, we can start labeling the states. Thanks. Excellent question.

>> Andrew Houtenville: New Hampshire is in the process of replicating this work. We may be six, seven or eight.

You mentioned emergency room visits, for the IDD population, dental. Emergency care for dental issues. CDC works closely with the Special Olympics, so that at special Olympic events they can have dentists, a tent or booth for people to get care. Those nudges you're talking about on how to interact with or find a dental practice that can handle someone who may be very uncertain about how do -- someone being in their mouth. It's not fun. That's an example, I think, of something, those kinds of nudges. That's a unique place where that nudge can happen.

The Medicaid program might not be good nudges.

>> Brian Armour: You're exactly right. Andrea and I were just at the world games last July. I'm not talking about dental cleaning. You were in those trailers. People in there are getting fillings, extractions. Unfortunately a lot of times it's folks with IDD, it's extractions because they may not get

the follow-up care from Jordan or Iraq or wherever. But I don't remember the numbers, I have them somewhere, by 7,000 athletes, I think 5,000 were treated for oral health issues. We have the numbers of extractions, etc.

There's tremendous opportunity. Within Medicaid, oral health is showing up. It's on the outpatient surgery side. We have the potential to really change not only how Medicaid thinks about this, and perhaps save money, but Special Olympics and others, what the priorities perhaps should be.

>> My question is for Brian as well. I was wondering how confident you are or who you think you might be missing using encountered claims data to identify people with intellectual disabilities if they're not necessarily seeking medical care for that per se. It may differ a lot across states depending on the type of waiver services they have or other types of services they might have for people with autism or intellectual disabilities. If that selection of people you can identify might influence your findings at all.

>> Brian Armour: In other conferences this is easier with one payer systems. In this country, it's particularly challenging. With Medicaid are missing some folks.

In other states, we can look, New York is another, New Hampshire is one, maybe you can do this in the future. They have what are called, I don't know how good these are, but what are called multipayer claims databases where you can kind of see who you're missing that may be covered by private insurance or someone else.

That's one of things we learned in our analysis. You're seeing people actually, in South Carolina, people covered by all types of insurers, but we're limited to Medicaid, because that's the expenditure information, that's how you want to follow up.

Your question is a good question, but I think if we get the final population it's like taking the stairs, that's the way to start it. If you're in the state that has these all payer claims databases, then you can figure out who potentially you're missing to a point. You still miss those who are really, really healthy. It's probably folks, in the case of IDD, probably with mild IDD that never show up as a diagnosis. They may still experience disparities in health.

It's a really good question. We are missing some folks. We have thought about it. It's a difficult question to answer. But I think when I show you I think in New York where there's 160,000 people and we're going to show there's opportunities to improve health, maybe that's where you start, then worry who you're missing later.

>> Andrew Houtenville: Yeah, in New Hampshire we're doing the all-payer claim status, people on private carriers, and it's about 20%. We're still getting to the data.

We're going to see the profile of their use of various services to see whether they're perhaps less likely to go to emergency room for preventable visit.

It's a rhetorical question in a way, or Brian's approach is we have to do something to move the needle. We can identify these people, follow them over time. If we miss people we'll try to figure that out, but we can't stop on this population to try to get a population-based statistics, as opposed to program.

It's important distinction between the population-based statistics from Census Bureau and NCHS and this claims data. I've had the same question when I first started talking to Brian about this. I've grown accustomed to it, for good or bad.

So I think it's a really powerful tool, but it's really difficult data, as you know.

Any other questions? Comments? Anything from the web? Is anybody still on the web?

[Laughter]

Art?

>> No, we're all set.

>> There are 89 people still logged in.

>> Andrew Houtenville: Thank you for those 89 people. I want to thank our panel. Kristi for coming out this afternoon.

[Applause]

Again, every year it's really interesting to hear the questions and to find out what's new and what's going on at the agencies. There's lots of rooms for advocacy with the revisions to HIS. We did almost lose the independent living when the census was evaluating. People were uncomfortable answering the dressing, bathing question. We were prepared to try to say OK, if you take that away, give us, split the question on cognition. So we save our same millimeters of space on the survey.

We didn't have to do that, but we should be prepared to in the future. I want to thank everybody for showing. All the questions. Again, we're available at disability compendium.org. We'd be happy to answer questions as you contact us. We want to thank our project officer Hugh Barry in the back. Next time, come to the front. Our funder, funding, Kristi Hill from ACL.

Thank you very much, everybody!

[Applause]

Those on the web, thank you. You missed out on a great lunch. There's plenty of lunch over there.