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STATE OF THE SCIENCE CONFERENCE
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ANDREW HOUTENVILLE: We're going to get started in a few minutes. We're just waiting to get the thumbs up from the recording people.

Thumbs down. So not yet.

Well, I don't have to wait for the recording to give you the logistics.

We were hoping to get name tags. Half of our boxes are in process, and unfortunately, UPS can't tell us anything because the tracking number is at UNH and it is closed, no one is home. They're all at their own home, not at work. So hopefully those boxes will be available when UPS delivers them in the morning this morning.

Some of the posters that we had planned for the posters that we were going to have out during lunch, some of those have not yet arrived.

And the national academy has been nice enough to print up an agenda for us.

So we're trying to make up for that loss of logistics.

We've also had a fair number of people, none of our presenters so far, be unable to travel. So we may get a steady stream of people coming in. We've also had various people from various agencies have to not come this morning when they were planning to come because of unanticipated meetings this morning as well.

Logistically, the bathrooms are to your right when you leave, right and then right.

The food will be out there all morning. So please help yourself to food and beverage.

Am I getting a thumbs up? Go up like this. I can't see your thumb.

[Laughter]

All right. Welcome, everybody. Thank you very much for coming out this Monday morning. All of us from New Hampshire had to make our early flights, move our flights up early, to get down here and we're happy to be here with you this morning.

First of all, I would like to make two thanks. I would like to thank first and foremost Penny Gould, who is probably out doing something right now, but Penny worked very hard to get this place up and running, this conference up and running, and we're very pleased that things are going not exactly according to plan but pretty close.

I would also like to thank NIDILRR, National Institute on Disability, Independent Living, and Rehabilitation Research, being NIDILRR, for their support financially and also their guidance and I can't use the word support. Anyway. NIDILRR for their financial support and also their teamwork in helping put together the statistic center that is putting on this conference so again, this is the state of the science conference.

Each cycle, each five-year cycle, we have a state of the science conference, and we're glad to have you here today.

I just have a few remarks to make about statistics and the work of the center before turning it over to David Wittenburg from Mathematica and Ruth Brannon from NIDILRR.

High quality, relevant statistics play an important role in addressing the disparities that exist among people with disabilities versus people without disabilities. And it's really not a direct role as much as it supports the efforts of others, whether it's in health, employment, independent living, medical rehabilitation. It really is one of the underlying factors that kind of supports both the advocacy and research endeavor that in part is funded by NIDILRR and other agencies and is driven by personal advocates and the public.

However, there is a divide that we see very acutely many times between the producers of disability statistics, so the federal agencies. Typically. There are some private sources of disability statistics like those funded by the Kessler Foundation, but there's a divide between the producers of those things and the researchers doing research with statistics and the end users of disability statistics.

So the general public, other researchers, policymakers, legislators, advocates, practitioners at the local level, and state level, who could utilize statistics in a way to help their practice, to help their work more effective.

And we see our role in the statistic center as kind of bridging that divide, both doing research with the statistics, both on how to improve the statistics, how to generate more relevant statistics for the users.

And then also to provide statistics to the users, provide support to the users. We have lots of technical support and technical assistance and dissemination activities that try to bridge that gap. So we have research to bridge the gap but also dissemination and knowledge translation activities to bridge that gap.

So on one side, you know, we have -- and if you're here tomorrow, you'll get to actually hear from all the main agencies that produce disability-related statistics in our panel tomorrow at the compendium release. Those agencies, there's been a tremendous amount of improvement over the years. You know, if you've been around disability statistics for quite a while, you'll know that, you know, it used to be the only main

information you could have would be from a work limiting disabilities perspective. Does a person have a condition where they cannot work.

But now we're up to six questions, which address a variety of functions and activities, and that's being included in a lot of other sources.

But with that, there's not a lot of data that's being generated from those things. Well, I should say there's lots of statistics being generated, but how to if get them and use them is still a mystery and still something that is being worked on.

So for the statistic center, we try to outreach every month. So we have the national trends in disability and employment with the Kessler Foundation. And we have a representative here. Good to see you, Elaine.

We have that every month. We also have a lunch and learn, a webcast at noon time eastern every month. And we also every year have our compendium release. So similar to this conference, it's a little more narrowly compacted to one day, we release the disability compendium as well as the annual report, which is more of a time trend, a summary of where things have been and where things might be going.

And then we have this five-year, every five years we have the state of the science. So we're trying to touch at all different levels and get into more and more detail. And really that's where you're at today. This is about the research about disability statistics. Not just in how to produce them or what the trends are, but also with how to use them. So we have some really great speakers. Susan Dooha is here from the Center for Independence of the Disabled in New York. She's one of the best users of disability statistics that we work with. We love providing her with data that can be actionable in New York, because if it helps New York, it will help other cities and locales as well.

But you're here to hear about our five-year update of the state of the science. And so I'm going to turn it over to David Wittenburg, who will talk about the state of the science and kind of the science end of that.

DAVID WITTENBURG: Good morning, everybody. I'm delighted to be here at the state of the science conference. And when I think about opening remarks to a state of the science conference, I think it's really important to tell a story about what the conference is all about.

As our team pulled together the state of the conference, we were very much interested in telling that story. Andrew began telling that story, and he talked about the producers of the data and the users of the data.

So today we're going to cover both groups in the four sessions today.

My job here is to really provide an overview of the four panels and why they fit together to hopefully arm you with ideas for questions to ask during these panels and at the end of the day form a comprehensive summary, not only today but also tomorrow after the presentation of the compendium and the policy roundtable.

So the first two panels are really about the producers. And they are about collecting and processing data. Those are going to take place in the morning.

The next two panels are about dissemination, to policymakers and practitioners. I think if there's a punch line to all of these panels, it's that, as you think about things like the compendium and the nTIDE that Andrew just mentioned, those are not static processes. Those are dynamic over time. If you look at the very first compendiums and look at compendiums now, they have changed quite a bit. The types of statistics we're presenting, the ways we're presenting the information, they represent changes in both data collection processing, the producers, as well as changes in the needs that the users have, particularly in things like info graphics.

The punch line for the state of the science conference five years from now is that they're going to continue to change because they have to change when we talk about statistics and disability statistics.

There are two fundamental reasons that they're going to change. First of all, technology changes. I think probably most of us are somehow tethered to a phone or screen or a computer, and that information is the way that we interact with the world, but it also changes the way we collect data from the world. And things like wearable technologies like fit bits and your phone are going to collect data on you in the future, usable data, used to inform policy, to make improvements to health outcomes.

The second thing that is going to change is that the needs of policymakers is going to change over time. This is inevitable. There's a need for rapid-cycle information, quick information, but also needs for different segments of the population. Disability is not a static concept; it's a dynamic concept.

So we shouldn't fear that change. I want to make sure I get this right. So this is the agenda.

ANDREW HOUTENVILLE: Page down again.

DAVID WITTENBURG: Okay. I took this picture from Twitter, and I was very entertained by it. It's a child that says, "What do we want? Evidence based science. When do we want it? Well, after peer review." I think that really summarizes what we want to do with the panels because it's not just about developing any data; it's about the rigor behind the methods, about developing objective data sources so that we can make true improvements in the lives of people with disabilities.

So I wanted to show this screen because in times of uncertainty, where we have to go back to is what we know in terms of collecting hard data and the need to review those data, so not just getting any data matters; it's the rigorous review of the data.

And hopefully what you're going to see today in the panels is the changing of that data.

So let me just jump in to some of the panels of what you're going to see. One of the first panels is the emerging options for obtaining data. Really what you're going to see in this panel are new options for obtaining, identifying, and using data. You're going to hear from a couple presentations using web-based options.

Web-based options have not been used very much for people with disabilities historically. So web-based panels are not innovations but the way they're being used for people with disabilities I think are going to be innovative on these sessions.

And this is really important. Not just for people with disabilities, but for people. Because the way we interact and the way we collect data is going to change. The times when we can collect 50-minute surveys using telephone and in-person follow ups are going to change. People have more limited attention spans and more limited desirability to sit for those types of surveys. So the way we collect data needs to change.

The second session is about linked administrative data, which gets to what I call processing. 20 years ago it was very hard to use administrative data because the computer processing of those data was really difficult.

Now, with the advancements of computer technology, we can process 20 million records very, very quickly. And that opens new doors. You have committees such as the committee on evidence based policy making looking to create a federal clearinghouse of administrative data.

So in this session you will get glimpses of what that administrative data looks like. You'll hear about that linked to social security administrative records, housing records, and so on.

So after that, we'll take you to lunch. This is perhaps the symbolic bridge that Andrew had mentioned. Take a break between the producers.

Then we will get into the users of the data in the afternoon, and we're going to talk about data to inform policymakers.

Here we're going to talk about the type of data that the policymakers need. We're going to peel back the onion and look at different segments of the populations of people with disabilities because there is no one single segment of people with disabilities. So the presenters will talk about the disability belts in the Appalachian Trail, emerging trends of SSDI beneficiaries, and so on.

And the final session is really going to be about practitioners and how practitioners use the data, particularly emerging needs with regards to WIOA, Workforce Investment Opportunity Act, but also emerging state needs, how states will be using data. This is going to be particularly important as we think about early intervention initiatives. And equally important, advocacy groups.

So tomorrow, Andrew will have an introduction of the compendium. Andrew and team, I should say, and Deb, and there will be a discussion following the compendium response by a roundtable of policy makers from the different house agencies.

To remind ourselves, the goal here is what are we thinking about here? Well how are the methods and processes changing and how are the needs for practitioners and policymakers changing and where should we go from here as a field. I think that these are the questions that we should be arming ourselves as we move forward with every single panel.

So we don't aim to answer every single question in this state of the science, but hopefully we answer several questions and we raise others and we continue to move forward as well as address this young child's needs of, you know, we want evidence based statements and we want to make sure that they are, indeed, peer reviewed and

rigorous and can be compelling to even the most skeptical audience. That is the job of the StatsRRTC.

>> Woo!

DAVID WITTENBURG: Thank you. I never got a woo. I'm going to put that on my résumé.

[Laughter]

I've got the, "when's it going to end," but thank you.

So I'm going to give a woo for Ruth Brannon. I'm delighted to introduce Ruth. I have been working with Ruth for almost 20 years now, and I have been extremely grateful for -- I wasn't sure of the time. But I was extremely grateful for the opportunity that Ruth gave me, because I came in to this as a very green researcher, and I think Ruth has provided incredible leadership at NIDRR and now NIDILRR, which is at a different agency. So I am happy to introduce her as the research director to talk about NIDILRR.

[Applause]

RUTH BRANNON: Well, I was listening to Dave and thinking the order should have been different, because he jumped right in to the heart of what you're here for and I'm going to digress a little bit as the funder and talk to you a little bit about what we're doing at NIDILRR in terms of disability data and disability statistics and speak very briefly about our move from the Department of Education, where we were for a very long time, into the Administration for Community Living, which is at HHS.

The NIDILRR mission stays the same. Our statute basically has stayed the same with the move. We're now authorized under WIOA, which Dave mentioned, and our mission is broad. It's to generate new knowledge and promote its effective use to improve the lives of individuals with disabilities to perform activities of their choice in the community, and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

That basically entitles us to do almost anything in the area of rehabilitation and disability research, and we have a very broad span of subjects from birth to death, every disability, and we are focusing -- we've chosen to organize this focus on three main outcome domains: Employment, participation, and community living health and function.

We struggled for a long time what to do about these two other categories, technology, which cross cuts everything that we do pretty much in rehabilitation and disability work, and demographics which is a term that had been in existence for a long time but really includes our statistics work.

We realized that because we don't consider these to be an outcome domain, we consider these to contribute to the outcome domains, so they are the encirclement of our three-center outcome domains.

I just checked with Andrew because I had forgotten to look up how many disability statistics RRTCs have we had? I've been at NIDILRR 20 years, and they were in

existence when I came, but he informed me that we've funded six, which I don't know if the intervals were always five years, but that's 30 years, almost the entire time that NIDILRR has been in existence, and it was part of the original vision for having NIDILRR as a separate entity and the importance of disability statistics has only grown over the years. We have been very fortunate with the quality of the centers that we've been able to fund, and I think the work that the current center does in terms of gathering the community to talk about why these things are important and the ways in which you do it, I think that's really a profound part of the service that we try to provide to the not just research community but to the ultimate user.

So strategic investments in disability statistics. I'm going to speed up a little here. Obviously this meeting and the compendium are very important. We support a development of major longitudinal databases. We have been working across the government in some areas in terms of developing and implementing common data elements, and we are very active participant in the White House initiative on data sharing, which will be implemented for NIDILRR grantees in FY17. So I'm going to talk briefly about these, not the compendium because you'll hear more about that tomorrow.

One of the things that we're very proud of at NIDILRR is our decades-long investment in longitudinal databases in three main areas that look at long term outcomes of individuals with spinal cord injury, TBI, and burns. The SCI database was established in 1973. It has more than 31,000 subjects who are followed across their life span.

The TBI database was established in 1987 and has more than 15,000 subjects followed over their life course. It is the largest civilian database of its kind in the world.

And the burn database which is the newest one was published in 1994, was established in 1994, and has now really over 6,000 subjects, and we're working very closely with the American Burn Association on blending with their data so that we can look at long term outcomes.

This work has really helped contribute to the broad understanding of what happens to people who have these very traumatic injuries in terms of their life in the community, their jobs, their health, their mental health. And we are now collaborating very closely with the DoD, the Department of Defense, and other agencies on these databases.

The data in the longitudinal databases has helped provide a basis for the work that we're doing about common data elements looking at common data elements, common data outcomes for traumatic brain injury, both for pediatric and adult populations. We've contributed to common data elements in spinal cord injury, and we're involved right now in preliminary discussions of common data elements in burn injury rehabilitation. Obviously our efforts are to come up with standardized set of outcome descriptions and embed those in all the research that's done so we can have at some gross level at least an understanding, a comprehension, of what has happened when science -- when we've done science in each of these three areas. And we are hoping to expand it to into other areas of our rehabilitation practice.

Public access for scientific data, of the implementation of NIDILRR, in some ways has already occurred because we are putting this requirement in to our funding opportunity

announcements that will be effective October 1, 2017. We work closely with the Office of Technology Policy to develop the requirements for grantees to make research data available to the public.

NIDILRR's plan was approved in ACL and is now under review at OSTP. We don't have any idea what's going to happen to this initiative, but we're assuming it's going forward. It has crossed different presidencies in terms of planning, and we were working on it when we were in the Department of Ed. So we are assuming this will become standard practice for all of our grantees. I think we're one of five agencies in HHS that has this requirement.

So I met with our staff to talk about what are the issues that might be addressed in this discussion that you're about to have both today and perhaps even tomorrow. What are we concerned about in the area of statistics. And I can speak as part of NIDILRR's management team that there's been some discussion about the redesign of NHIS, what's been dropped, what are the new items, will there be a reasonable number of disability items; that's been an issue on our mind. The future of the American Community Survey as the standard collection of disability data elements. Are there changes in the works. There's a lot of talk around that. The work of the Washington group on developing a disability module for use in labor force surveys. What are the implications of this. We're very interested in finding out more about that.

So I think some of you, if you follow us at all, know that we published a draft long range plan about a month ago that is a statutory requirement that every five years we publish a long range plan. We were able to get it published with the guidance of John Tschida, who was our director. He's a political appointee so he's not our director now. Dr. Kristi Hill, who is our deputy, is acting as the NIDILRR director. So we do have a section on disability statistics in there. If you haven't looked at it, I urge you to take a look and make comments to us.

But these are the core descriptors from that part of the long range plan in terms of the way disability statistics matters to us.

First, policy decisions. Obviously we're very interested in forming policy, practice, and programs. Demographics identifying changes in the characteristics of people with disabilities. Prevalence and context, contributing to understanding changes over time. Service delivery, inform service delivery, what's needed. And current and emerging needs to identify future research directions.

So please, take a look. Make any comments. Help us make it better. We hope to be able to publish a final version of this sometime in the future.

So for further information, you can contact me or Dr. Phil Beatty, who is sitting back there, the deputy research director. I'm looking around, there are at least 4-5 NIDILRR staff in the audience and I think a couple of more to come. So we're very proud of our investment and very happy that we've been able to continue it and we think it has had an important impact on the quality and availability of statistics to help us understand the needs and the strategies that we can use to meet those needs for individuals with disabilities.

Thank you.

[Applause]

ANDREW HOUTENVILLE: Thank you, Ruth.

So we are going to move straight into the first session, the first panel.

We do have a slight change. We have a switch of Davids. So David Keer, former NIDILRR project director and one of my first people at NIDRR that I got to know, is unable to make it. And David Wittenburg has just about three minutes ago agreed to replace him.

[Laughter]

So I'll call up Eric Lauer, Kimberly Phillips, and Jesse Chandler for the session, and we'll take a few minutes to get settled.

DAVID WITTENBURG: Hello, everybody. There's a quota on the number of Daves per conference. We were at four and we're back to three.

First session is emerging options for obtaining data collection. We've got three presenters here: Eric Lauer from the University of New Hampshire is going to talk about identifying people with disabilities in the federal service. This is the natural starting point, the traditional way of producing disability statistics and it will be continued to be the prominent way.

And then we're going to move to Kimberly Phillips from the University of New Hampshire, who will talk about what I would call the transition from web versus traditional survey methods and talk about some of the tradeoffs that we have in terms of the different methodologies.

And then finally we have Jesse Chandler from Mathematica, who is actually going to show a pilot of the web-based service, sort of the movement from traditional to more nontraditional in terms of application of data collection and attempting to identify information at a low cost method.

So Eric, I'll turn it over to you.

ERIC LAUER: That's not my talk.

[Laughter]

I fixed it.

[Laughter]

DAVID WITTENBURG: Let's wait for the evidence to emerge.

[Laughter]

ERIC LAUER: Good morning. My name is Eric Lauer. I work with Andrew Houtenville at the institute of disability at the University of New Hampshire, studying and producing disability statistics.

What I am here to present to you today is some of our work studying the, I guess for this talk, the consistency of disability estimates that are produced using standardized disability identifiers that can be found in national surveys.

Many people know, but just to give a little background, the result of having standardized disability identifiers in national surveys is the result of decades of advocacy and work. It culminated with standardized question set that, in part, was motivated by healthy people objectives, the first healthy people objective is to have a way to identify people with disabilities in national surveys. It was, in part, informed by questions developed with the Washington Group. And it resulted in six questions that were used to respond to the mandate by the Affordable Care Act, which recognized people with disabilities as a minority population, at risk of experiencing disparities in health and inequities.

These questions are consistent with the international classification of functioning disability in health and really highlighted the perspective of the individual, their experience, limitations in activity, function, and participation.

Recent research in the last few years has tried to promote the use of these questions. Because while they are slowly being rolled out in every national survey that people with disabilities respond to, there really is not a lot of peer review publication using these questions. The NIH produced a publication several years ago talking about how these questions can be used with data from multiple surveys to study function in disability very consistent with the ICF. When you look at surveys such as the national health interview survey, the survey of income and program participation, you really start to be able to look at the intersection of how people function and how well they can participate in programs and services.

These six questions, the topics are presented here. They ask people to report whether or not they have serious difficulty in various areas, including hearing, vision, cognition, ambulation, self-care, and independent living.

With that in mind, last year, two years ago, we really set out to take at the time the current surveys that were including these questions, look at the consistency and look at the consistency of estimates over time and take a cross section of the 2011 survey for each -- 2011 data sets for each of these surveys, and look at not just the overall prevalence estimates but look at disparities and inequities related to social determinates you can measure and see how consistently those were being estimated.

The four surveys we included that you'll see here include the current population survey, the American Community Survey, the national health interview survey, and the survey of income and program participation.

This slide presents the prevalence, the weighted percentage, of people, of adult noninstitutionalized civilians identified as having a disability using these questions by survey and year. Vertical axis is percentage, and horizontal axis is year.

You can see that within survey, the estimates of people with disabilities is fairly consistent and for the most part nonsignificantly increasing year to year.

However, when you do see across surveys, you notice a substantial difference in the estimates that are produced.

After this slide, I'm going to start to show you a breakdown of those six questions, and one of the consistent themes that's reflected in this slide is that the NHIS consistently produces the largest estimate, and the CPS consistently produces the lowest estimate. While the range, for example, in 2014 was between approximately 12% of people estimated using the CPS and 17% with the NHIS, you will see those similar types of ranges and differences within each question.

This is a similar slide as to the one before. And this looks at vision difficulties or vision disabilities that are identified across the four surveys. I'm going to start to move a little more quickly only because I'm not as focused on the exact percentage as much as showing the consistency of estimates and the range of estimates for each disability type.

There's a consistent difference you'll see of approximately 2-3% for each estimate with the NHIS, again, appearing as the largest estimate and the CPS appearing as the lowest estimate.

Again, this is hearing disability. Slightly larger range. NHIS and CPS creating the bounds of the range of the estimate.

This is the estimate of cognitive disabilities. Similar range.

This is ambulatory disability.

This is self-care disability. Slightly narrower. Self-care disabilities are typically the smallest percentage identified across any survey of disability types, of the six disability types we're identifying with these questions.

And this is independent living disabilities.

Once we had looked at the time trends and the consistency of those six disability types over the years, what we thought was a good next step was to look at the demographic profile of people with disabilities in each survey. Especially since disability is such a heterogeneous population, it was important to figure this out.

What I have here is a slide of the distribution of age, of people reporting a disability, across these four surveys. Again, I'm not focusing on the percentages as much as to show there's a fairly consistent age distribution within each age group for all four surveys.

And I don't have slides for this here due to time constraints, but we found that gender and race were very similarly estimated in the sent that they're consistent. Similar percentages of men and women and non-Hispanic, whites, blacks, Asians, and other categories as well as Hispanics.

The measure that overlaps with, unfortunately, my vertical description is marital status on this slide.

The next step presented here was to look at some social determinates and see whether or not the magnitude and the direction of disparities that people with disabilities have been shown to experience are consistently measured across survey. So the vertical axis is weighted percentage, and the three groups, three measurements being estimated are employment, marital status, and poverty.

What we again can see is that the magnitude and direction of these disparities are fairly consistent. There is some statistically different measurement and I'll get into what that even means in another slide or two, but the overall measurement is very consistent.

To summarize the last couple slides I've shown you, estimates of people, prevalence estimates, vary significantly between survey but are very consistent within survey over time.

Individual estimates of disability type vary by approximately 2-3% per type across survey.

And consistently the CPS is the lowest estimate and the NHIS produces the highest estimate in these surveys.

In our internal analyses, we found that the reporting of disability was highly dependent on age. This has been shown before, but what we found was one of the things we found and started to explore is the fact that disability is not a part of the weighted in these national surveys. To take a step back, I'm going to talk a little bit about what could drive some of these factors that would explain -- what could drive some of these differences I've shown you here.

One of the things we found that could explain those large variation in prevalence that I showed you at the beginning of the talk is this idea that disability is not included in this part of the weighting scheme of the surveys. When you look at the underlying unweighted population, just the people they ask, if that group is younger than the census in a given year, and the weighting, the way we make that survey representative of the United States population, makes them older, that will drive the disability estimate that is associated with the change.

So what may be happening to drive some of this variation and some of this change within survey and within type -- sorry, between survey and between type, is the underlying sample year to year.

What this suggests overall is that survey design and context affects impact responses. So it very well may be that who the NHIS asks and the fact that the entire survey is focused on health may end up producing the largest prevalence estimates. Who the CPS asks and the fact that it focuses on employment may minimize the estimates because people aren't as primed to discuss their difficulties.

These results also show that the disability questions have very strong predictability. You consistently see disparities. You see disparities that are very consistent and similar in magnitude and direction. And this estimation is highly dependent on age. And the underlying distribution of who is being asked in a given sample and a given survey.

There are a number of limitations to this type of the estimates I presented here today. The most important of which is that it's very difficult to measure error in these surveys and it's very different to then compare the statistical significance and variation and determine what might be driving that. While we found a few things such as an association with the underlying unweighted sample of just who randomly gets asked, drawing conclusions about this and talking about what else may affect it is very difficult.

I see that I've run out of time, so I think I'm going to stop here.

We have a few recommendations coming out of this work. The first is to where possible, use multiple years of data. There's now at least seven years available for most of the surveys I've presented here.

Include age and disability type in most of your analyses since we do see some amount of variation.

Consider evaluating your unweighted Sam size and who is actually asked these questions by survey.

And consider the underlying survey context and design when using these questions and recognizing that that may drive some of the estimates you produce.

Thank you.

[Applause]

KIMBERLY PHILLIPS: Good morning. My talk this morning is random digit dial versus web panel: Employment survey sample comparison.

I will be discussing results of two different ways that we collect and survey data regarding employment and disability. I would like to acknowledge NIDILRR for funding the current work that we are doing as well as past work including the random digit dial survey I will describe funded by the Kessler Foundation.

Also thank you to my colleague Nick Rollins for providing me with a lot of the statistics that I will share.

So brief background. Random digit dialing surveys were for a long time the premiere mode of national polls and opinion surveys, particularly in the times before cell phones were ubiquitous and before we had the technology to carry out online, mobile, and web surveys.

However, more recently there have been some problems with RDD. It started to seem a little bit less attractive of an option, and that is because of steadily declining response rates, the aforementioned ubiquity of cell phones, which means that there are additional complications in reaching telephone samples as well as creating analytic weights to make those samples nationally representative. Both of these contribute to increased expense.

At the same time, the development of web-based applications has presented a new mode for survey data collection that is not only increasingly simple for survey developers to use but very easy for respondents.

And paneling, which means that the survey software company, such as SurveyMonkey, they maintain a captured sample that they have in essence prerecruited and that these people of all kinds of samples really are readily available for researchers.

So our goal with this research and this talk was to find out what do we gain and what do we lose if we choose a random digit dial versus a web-based survey mode. And in order to answer that question, we compared samples from a national survey conducted using each mode, and we referenced both to ACS benchmarks.

The data sources for what I'm about to share, the RDD sample resulted in the publication of the 2015 Kessler Foundation national employment and disability survey, and David Wittenburg will be pleased to know that another paper summarizing the findings was just accepted for peer review publication.

DAVID WITTENBURG: Very happy.

KIMBERLY PHILLIPS: And then the web survey is a paper in progress. For that data, we used a Qualtrics sample called their health conditions panel.

Both of these surveys resulted in 3,000 complete responses from adults between the ages of 18-64 with at least one disability.

On to findings. Just an introduction, don't worry too much about trying to digest all of these numbers; I am going to direct your attention to specific areas and I will also show some graphs. So you'll see this visually and hear it aurally as well.

The random digit dial statistics are in the first column. The web statistics are the final column. The ACS benchmark is in between.

This is unweighted data. So first we want to see just who answered these surveys before we did anything to it.

Right away you see that the web survey was more heavily female.

Moving to the graph, the solid thicker line is the ACS. The dashed yellow line is the web survey. And the dotted red line is the random digit dial.

So, again, unweighted data. We see that the web survey tended to be a little older, and that's because there were fewer respondents in the 18-24 range and more in the 55-64 range.

Regarding race, both the web and the RDD surveys were more heavily white and less black. However, they were comparable to each other and to census prevalence on other races as well as multiple race.

And region. The web sample was more likely to come from the north and quite a bit less likely to come from the south.

So now we'll move to weighted data. These are the four variables that we weighted on. Gender, age, race, and region. We tried to match as near as possible the same with RDD and web, but the RDD also weighted on specific things related to telephone

surveys such as number of telephones, size of household, etc., but this is as close as we could come.

The short story is, weighting worked very nicely. So you can see immediately that gender is now equivalent across survey modes and all three of these lines now are basically right on top of each other, meaning that they match for age as well as race as well as region.

So what about the variable, certain key variables that weren't used in the weighting process? We looked at disability type. So the questions, the disability questions for the telephone and the web survey were identical, and they were both very similarly worded to the ACS questions. Here we're looking at the four functional disabilities from the census: Hearing, vision, ambulatory, and cognitive. And again, this is using the weighted data.

What we see is, both the random digit dial and the web survey had a higher prevalence of both hearing and vision disabilities. In fact, the RDD had a higher prevalence of all the disability types, which suggests that more people responded or answered that they had multiple disabilities in the random digit dial survey.

The web matched the ACS benchmarks on ambulatory and cognitive. And I want to draw your attention real quickly to how similar the two surveys are on cognitive disability. And this is interesting because the random digit dial survey allowed for proxy responders. But the web survey didn't. So 18% of the RDD responders were proxy or an adult that was speaking without a disability that was answering on behalf of an adult with a disability who was unable to or unavailable to at least but supposedly unable to answer the questions on the phone themselves.

And that was mostly people with hearing disability, which makes sense if they didn't have relay or accessible phone set up.

And then second most, for people with cognitive disability. So another vein that we won't talk about right now but we're investigating because is it that a cognitive disability is such a broad term that perhaps proxies were responding for people with, for example, intellectual disabilities and so we had more people with I DD represented in the random digit dial? Where maybe we have more people with psychiatric or mental health disabilities in the web based panel? We don't know, but stay tuned. That will be interesting to examine.

Moving on. For currently employed, again, we looked at current employment percentage by disability type, and what we found is that the RDD, the people with hearing and vision disabilities were somewhat less likely to be employed than we would expect based on census benchmarks, and all the disability types except hearing were somewhat more likely to be employed among the web sample. But they're pretty close.

We looked at two other socioeconomic factors here, education and annual household income. This is my favorite awesome spider-looking figure. But what it says is that both the RDD and the web survey are more highly educated than we would expect from the general population. Especially so for the internet survey, which makes sense because internet usage is correlated with education. But both had fewer people who hadn't

completed high school and more people who had completed a four-year college or more.

And regarding income, the lines are pretty close, as you may be able to see, but the web and RDD surveys both did not capture as many people in the highest income bracket that we looked at, so $100,000 a year and up, and for some reason the RDD captured more people in the lowest income bracket, less than $15,000 a year.

In sum, although I just went out of my way to highlight some of the differences, both modes approximate ACS bench marks fairly well. Sometimes they look the same as each other; sometimes they diverge a little bit.

I'm thinking real quickly whether I should resay the main points, but I will.

Disability type, they both had more hearing and vision. The RDD was higher on all. And they were all similar on cognitive.

Employment, RDD had lower employment rates for hearing and vision than we would expect. The web was higher on employment for all except hearing.

Both RDD and web were more highly educated.

Both did not capture the higher income brackets, and the RDD had a little bit more in the lowest income.

So given that both survey modes performed comparably well, our team's intention is to move forward with web-based surveying. I mean, this is pretty exciting, to find that a web-based panel, which is a captured sample, prerecruited can look so similar to a random digit dial that was the gold standard for so long.

But we're going to move forward on this for three reasons. One is cost savings. 3,000 complete responses from the panel survey cost literally one-tenth of 3,000 complete responses in the RDD.

Similarly, speed. We had these 3,000 complete responses from people with disabilities in less than 10 days for the web sample, and I don't know exactly how long it took for the RDD -- well, I know how long the project was, but I would -- really? Data collection took more than a year?

>> Two and a half months.

KIMBERLY PHILLIPS: Oh, okay. I thought you said two and a half years.

So two and a half months. Okay. I think it was longer than that, but that's okay. I'll argue with Andrew later. You know, because when you add in pilot testing and so forth, but our 10 days was including pilot testing, because you can do pilot testing in an afternoon.

Okay. And finally, others are doing, including the U.S. census. We are moving towards that direction and we are happy to follow along that path.

A couple of parting comments. Despite similarities, of course they're both samples and neither will be perfect. We hope that people will replicate this work and we ourselves

will replicate it as well. Regardless of your mode or sample design, we will continue and we hope that others will benchmark to the ACS. It's really a great way of helping to judge what our samples are looking like and what we can do with them.

With the web of course, this benchmarking can be done either before or after the survey. So we can set quotas, which we didn't do with this particular time, but we could say, for example, we want X number of women who are African-American or black between 35-44 and who live in the south. Once we hit that, great. Or we can use analytic weights as we have done here after the survey.

And finally, to do this benchmarking comparison, it's important that we ask disability questions in the same way as the ACS in order to facilitate comparisons.

Thank you.

[Applause]

DAVID WITTENBURG: We will have 15 minutes for questions. Everything is rolling smoothly.

JESSE CHANDLER: Hi, everyone. My name is Jesse Chandler from Mathematica Policy Research. Today I'm going to show you results of a study where we looked at the feasibility study of recruiting and maintaining a web panel of people with disabilities.

This specific population today is vocational rehabilitation applicants.

There are three different goals of the study, three things we were trying to achieve. The first that we were trying to investigate is this panel recruitment rate. Unlike Kim's study, where she was looking at an opt-in panel, we wanted to know, if you go out into the field and ask vocational rehabilitation applicants are you willing to complete a web survey, will they, in fact, agree, and if they do, will they, in fact, actually complete it.

We were also interested in panel retention rates. What I mean by this is once you get people to complete a survey, can you get them to hang around and complete a second survey further down the road. This is really important if you're interested in following individuals' trajectories over time.

We were interested in number of people and also differences between the kinds of people who may be completing web surveys versus those who aren't.

And finally, with this particular study, we're also interested in trying to identify some of the logistical challenges you can run into when fielding a web survey for people with disabilities and I'll get into those at the end of this talk.

As Kim alluded to, there are many reasons why web panels are attractive. First and perhaps foremost, web surveys are very cost effective. The cost of producing a web survey are largely fixed and involve programming the instrument. Once it's built, it scales up nicely to recruit large samples.

Web surveys may also make it easier to maintain contact with individuals. If somebody moves or if their phone becomes disconnected in a longitudinal survey, you lose contact with those individuals, it can become expensive to locate them. In contrast, people's

web presence is often permanent. If they change their email address, it may be independent from changing their physical contact address.

And finally, web panels may be more convenient for at least some participants. You don't have to schedule a time; they can complete it at their leisure at the time of their choosing and also either all at once or in different increments, whatever is best for them.

All of these benefits scale up for panel surveys when the efforts of contacting people become more difficult and the burden you place on respondents becomes higher.

There's a number of reasons to be concerned about implementing a web survey when studying people with disabilities. There's a digital divide. Right off the bat, about 13% of Americans don't have internet access. When you're conducting a web survey, you're missing some element of the population from the get go. And there's a disparity between people with disabilities and not. People with disabilities are even less likely to have internet. Some reasons are because of demographics, the correlation between having a disability and not having internet access. People with disabilities tend to be older, and people who are older tend to have less internet access. People with disabilities may have had less education and less exposure to technology that way. They also tend to have lower incomes which places material and resource constraints on them that may limit their internet access.

Above and beyond that, the direct effect of having a disability can add difficulty to the experience of getting online as well. Something like 7% of people with disabilities say that their disability makes it difficult or even impossible for them to use the internet.

And all of these things are important because what I want to suggest is that even though people who don't have internet access are the same as people who can complete an online survey in some ways, they may differ in ways that are of policy relevance. People without internet access, their experience of engaging in government services or finding out information about healthcare will be qualitatively different from the experience of people who have internet. They're missing this entire other means of gaining information in the world.

On top of that, there is some evidence to suggest that people who lack internet access have other ways that impact policy relevance. For example, people who lack internet access often report having less social support in general and thus may be in more need of government services or may have particular needs that should be addressed.

That said, there's also a lot of reason for optimism. After giving you all this depressing news, we're going to shift and I'll show you a picture of a baby to kind of lighten the mood a little bit.

What I want to suggest is that in general it's becoming easier to use web technology, right? So over time, costs of getting online are lowering, and the learning curve for using new computing technology is becoming shallower and it's easier to get online. For that reason, we thought the time would be right to give people internet access and see what would happen.

As I alluded to earlier, this particular sample is a sample of vocational rehabilitation applicants, recruited from Mississippi, New Jersey, and Ohio. They had all completed a previous survey for Mathematica.

All of them agreed to be contacted again, so that's what we tried to do.

About two-thirds reported that they had internet access. Another 28% had limited internet access, which means they maybe didn't have it in the home but had a friend or family member with internet access or they could get online in a local cafe or library. And 7% of the population said they had no internet access whatsoever.

We recruited three different groups of participants. 90 people with internet, 90 people with limited internet, and 30 with no internet.

They were all given a tablet, sort of entry level, about 10 inches in size, weighs about a pound, pound and a half. The cost of doing this, each of these units costs about $100 to purchase. So we gave them the tablet as well as wireless internet access in their home for the duration of the study.

In this particular study, what we did is recruited people by phone. About a month later we tried to get them to complete the first web survey. Five months after that, we had them complete a second web survey.

What I'm showing you here are just the recruitment numbers. Because we were recruiting a small population of people, we dialed through people who had previously done surveys and hit our quotas.

Two things to highlight here, first, people with limited internet access are less willing to participate in this study, probably because we're asking them to do something that's harder for them. We're asking them to kind of trudge down to the library and fill to out a survey there.

Another thing I want to highlight that's really important is when you look at the number of bad numbers, disconnected either temporarily or permanently, people with limited internet and no access had more disconnected phone numbers. I think this highlights that these groups, maybe there's some sort of underlying economic instability driving the intermittent phone access and internet access.

So each survey was released with two email reminders, and then we called participants 1-2 times a week asking them to complete the survey.

Another thing we did, after the web survey was complete, we moved to the phone and tried to get people to complete the survey who were will to do so but just not online.

If we have questions later, we can talk about what's involved in getting people up and running who have never used the internet before.

I will skip the response rates. The take home point here is that people tend to have mode preferences. People who like to complete the web surveys tend to do so both times, and that's consistent with those who prefer the phone as well.

Over time we were able to attain about a 40% completion rate in terms of the web survey and 67% completion rate overall.

A couple of things I want to highlight here. The first thing you'll note is that people with limited access are about 30% less likely to complete via the web than people with internet access at home. This probably reflects the additional hassle of completing online, but when you provide tablets for people who lack internet access, not only are their completion rates online higher than the group with limited internet access, but they're also not statistically different from the group who have access at home. So basically giving individuals tablets erases the sort of gap, you know, providing you assume that people with no internet access would be less able to complete the survey online than people with limited access.

When you look at the total completes rates, that gap persists even after you go after the remaining sample via phone. This suggests that the gains you get from providing internet access to respondents can't quite be offset just by more intensive phone efforts.

Demographics. I want to call your attention to two take home points here. First of all, the overall completes, the sample looks a lot like that we were recruiting from, small differences but nothing that can't be corrected through weighting.

But if you look at web completes versus those by phone, it becomes clear that those who tend to complete via web than the phone tend to have higher incomes. They also tend to be more likely to be women. You know, both of these findings line up with what Kim was discussing earlier.

Looking at type of disability, we find some results that are slightly different. I high light two here. People with vision-related disabilities seem to prefer phone surveys, whereas people with hearing-related disabilities tend to prefer web surveys.

One thing we noted is there seems to be differences in terms of people's experiences that they're reporting in terms of VR application processes in these surveys. Generally speaking, people who completed by the web were more likely to say they had been contacted about their VR application but they also reported that they were less satisfied with their overall experience.

At this stage we can't say a lot about whether that reflects differences in the kind of people who reply or whether there's something about talking to a person that kind of changes the responses people are giving. But it suggests there is important considerations in terms of the responses that you're getting and that these feed into your decision about which mode to use. Definitely an area for future research.

In terms of lessons learned, you know, there's a number of practical difficulties we didn't anticipate when working with this population. We lost something like 10% of the tablets we shipped to respondents via the mail. As it turns out, when you waive signature requests, you waive them permanently. It's often inconvenient for people with disabilities to go out to a UPS delivery center to pick up their packages, so many individuals had waived their signature requirements and maybe unknowingly permanently and had tablets left on their doorstep that subsequently vanished.

We also had a fair number of broken and stolen tablets. Two were broken with relative live minor fixes, like broken chargers or something. But theft was also a problem. Both lost tablets and stolen tablets are things that need to be allowed for if you're going to do this type of data collection effort where you're giving people tablets and waiting for them to respond.

I strongly suggest buying more than you would need if you do this because this kind of data collection effort becomes very complicated if different respondents are using different types of equipment.

Difficulty using the internet remained an issue for some individuals in the no access group too, so it's important to provide technical support to help people remember how to log in to their email and stuff like that.

We were able to look at data use. We weren't monitoring what respondents were actually doing online, but we were able to see how much data they were using. There's a very bimodal distribution. About half the sample stuck this tablet in their closet and that's the last we heard of them, and about half used much data watching cat videos or doing something like that when not busy completing our surveys.

But by and large it seems like the hassle of getting online was also a major issue for the limited access group. If we could do this again, I think it's worth thinking about providing internet access for that group. The people who reported having limited access were people who clearly knew how to get online and were interested in doing so but there is this barrier practically preventing them from doing so.

I think take home points, web is great. It's cost effective when the sample is large. It drives down cost per complete.

And it seems to do something, adding this extra mode, in terms of improving overall response rates.

But there are differences in respondents using different modes so I think that's a caution against moving to a unimode web only survey. I think the right way to look at the web survey is as a complement to phone surveys to drive down cost.

And whether you've should provide people with internet access by giving them tablets is more complicated. The hardware itself isn't expensive, but providing internet access through a wireless plan becomes costly.

In communities where web access exists, this is a good idea, but if you're maybe interested in a rural population where the cost of providing broadband access is expensive, that's really something to consider. That actually turns out to be the major cost driver for this sample.

And just to give you a sense of what it took in this particular study, providing six respondents with tablets and wireless access basically would drive one additional complete for the limited access group. So again, it's a kind of expensive solution and suggests that maybe providing tablets and access is not appropriate relative to recruiting those individuals through phone.

All right. Thanks, everybody, for your time. I don't want to stand in the way of questions so I will wrap it up here. Thanks a lot.

[Applause]

DAVID WITTENBURG: Okay. We've been talking about response rates. I hope we can get questions from the audience.

Yes. Do you mind going up to the mic? Do we have a roving mic?

>> Hi, yeah. This is a very loud mic.

My name is Diego. My organization is interested in working with young people on entrepreneurship and employment. This is interesting to me because we primarily work on web and mobile interactions.

So I have a couple questions. First, I saw that there's a disability statistics report from Cornell University. I'm wondering, is this -- how is this different from what they're doing? Are you guys working together? Or not? Just wondering because I saw that as well. So that was my first question.

My second question is, for the web work, have you guys tried to look into mobile interactions? Because that might have a better, you know, a lot of people might have access to mobile interactions while they may not have access to web. So that might be an interesting point to consider.

And then my last question is, have you looked into any data mining of where people are already kind of hanging out? Because I think it's interesting if there's a way to collect data in the day-to-day interactions that people with disabilities are already doing, so for example, every time we take an Uber or use Facebook, is there any way to mine that data and look at it in real time?

DAVID WITTENBURG: All right. We have three questions.

ANDREW HOUTENVILLE: I'll answer the first one. I used to be at Cornell for years. That status report is really restricted to only ACS data. The compendium, which you'll see tomorrow in the annual report are based on lots of different data sources. So it's scraped together. Almost like a scraping aggregating process. You know, what a statistical abstract used to be for the United States. So it really pulls from all data sources that are really possible.

I'll let others answer the other questions.

DAVID WITTENBURG: Anybody want to take the mobile question?

KIMBERLY PHILLIPS:

Yeah. So question two, Diego, I sort of made clear in my talk, when I called it RDD and web, our web survey was fully active for mobile technology as well. So when going in to even create a survey in Qualtrics, for example, it shows you the layout, what it will be like to respondents using a computer, tablet, or smartphone, so you can mobile optimize.

>> Just to clarify, I mean text message, SMS.

KIMBERLY PHILLIPS: Oh, okay. So text message. So what was the question?

JESSE CHANDLER:

So was the question have we looked into using SMS data collection?

>> Yeah. Because you don't require -- sorry. Thank you.

You don't require internet access if you're doing text messaging. So that may be an alternative to make it more accessible to other people.

KIMBERLY PHILLIPS: That is not something we have experimented with yet.

JESSE CHANDLER: So I can say, and maybe I wasn't clear about this in my talk. I do think one of the major barriers for people with disabilities is the sort of issue of income. And I think that's partially what you're getting at. Data plans are expensive, right?

To my knowledge, Mathematica has not looked at studying populations of people with disabilities using SMS, but we have used that successfully on other populations that have similarly low income. So that's definitely an avenue worth exploring.

I guess the other way to think about this though is that the cost of wireless access are continuing to fall, and this is one of those problems that may also solve itself relatively quickly, but it's an interesting avenue to explore for sure in the short term.

I wanted to take a shot at the third question too. We have not done anything in terms of mining online data, but I can tell you there are people engaged in that kind of research. I have seen papers looking at Reddit communities, for example, and mining Reddit discussions to kind of understand what kinds of issues people with disabilities are talking about there. And I'm sure that there's papers similar on Twitter. If you want to find me during the break, we can exchange contact information and I can send those to you.

DAVID WITTENBURG: A question back here.

>> Great. Thank you all for your presentations.

I'm Phil Beatty from NIDILRR. After hearing your presentations, I have to say I'm excited about the possibility of web-based panels and web-based surveys.

And I hope this isn't a silly question, but a lot of things were going through my mind as I heard you speak.

Ultimately I'm concerned about the quality of data being used to support policy and practice decisions. But as a research-sponsoring agency, I'll tell you what was going through my mind. I'm concerned about receiving grant applications that propose web surveys. And I'm concerned about the ability of peer reviewers to distinguish between well paneled, systematically created web surveys and then those fly by night convenient samples that you really can't generalize to the populations that we're interested in.

So what is our -- and by our, I mean our responsibility as a field of experts to have standards, create standards, and educate the field about standards so that the work that you all are doing isn't just lumped in with the millions of web surveys that are being done by lots of people and promoted as fact?

KIMBERLY PHILLIPS: That's a great question. I don't know who wants to answer that. Do you, Eric? Do you have any thoughts on that?

DAVID WITTENBURG: Could you speak into your mic, Kim?

KIMBERLY PHILLIPS: Oh, sorry. I thought I was.

I think that's a great question. I'm looking at my copanelists to see who might want to share some thoughts on that.

I think it's something we need to come together to discuss, right, what are the best ways to judge the quality of online web-based panel research. We could certainly talk about some benchmarks for you such as is it a verified sample, do we know that people are who they say they are. Of course there's going to be the statistical methodology that's used in analyzing the results of the survey. And whether there is any bench marking or weighting going on and what are those weights based on and what's the, you know, expertise of the analysts in that area.

And I think track record with survey design itself. Because it is point and click. Simple to create an online survey. Does that mean it's a good one? No, not necessarily.

So I think some of the standard probably what you're looking for expertise applies, and then there's just a bunch of new things that have not yet been created and I think having maybe an expert panel discussion about that, the way that I know Andrew and many others talk about disability data in general, that should be a topic that gets added on, in my opinion.

JESSE CHANDLER: I just want to add to that. I don't think it's necessarily -- to go to your comment about how you evaluate as this in terms of evaluating grants, I don't think it's necessarily an either/or decision. This is my own personal view. I see the role of online convenience panels complementing existing data collection efforts. It's an opportunity to fail quickly or to try out an idea quickly before you invest the kinds of resources necessary to collect a high quality comprehensive population survey.

So I guess the questions I would be thinking about are --

[Laughter]

-- before you invest in -- you know, high quality population surveys are very expensive, not only in terms of financial resources and the opportunity costs that go with that, but also time. I would think of online panels as ways to find out information that what you think you want to go is a terrible idea or maybe a promising idea right off the bat. You can find that out very quickly and that could be used to guide and inform the kinds of population-based surveys that you do.

So I don't think you have to choose between one and the other. I think the web component is potentially saving you from making a potentially expensive mistake and fielding something that's fundamentally flawed.

In terms of adding a web component to an existing phone effort, my talk focused a lot on the ways in which phone respondents -- or web respondents, might not be representative of the population as a whole. But as time goes on, people not responding to phone interviews won't be part of the population as a whole particularly as people drop land lines. So I think we're almost to the point where you want to have some sort of mixed mode data collection effort to make sure you're not losing out on particularly younger survey respondents.

DAVID WITTENBURG: Andrew, how are we doing on time?

ANDREW HOUTENVILLE:

Two more questions.

>> Hi. So I've used -- I've analyzed a couple web-based surveys. Both were developed by people who had been doing random digit dialing for years and have moved to web based and found a couple things.

First of all, the overall prevalence of disability is really, really high. And I was wondering if perhaps the reason was because in something like the CPS, you ask a householder about the whole household, where in a web-based survey, you're asking the individual respondent. That was one thing.

And also I'm kind of interested in how you guys feel about the payment that is going with the web-based surveys, because I think that all the for-profit firms have some kind of incentive that they're giving their respondents and I'm wondering if that's changing who is answering the survey.

And the other thing I found that I think we should all be aware of in these is that people tend to yes at the end of the survey. So what I found in both, I found shocking in both surveys, that I had a bunch of people say "yes" to the last, you know, third of the survey. And if your disability questions are at the end, there's a lot of people with six types of disabilities.

[Laughter]

ERIC LAUER: So I'm not sure --

>> And it's also interesting, you should also probably look at how weighted they have to be. Like I was surprised at, you know, if your average is 1, I had one survey that was weighting some things at .05 and some people at, you know, 32.

DAVID WITTENBURG: So Nanette, is your question really --

>> It's like how valid are they.

DAVID WITTENBURG: How do you design questions --

>> It's a how valid are they and am I getting a really high prevalence rate because of the difference between a householder responding for everybody and people responding for themselves. Why is my prevalence rate so high is really the question.

ERIC LAUER: So surveys such as the ACS are also using the multimodal design, including a web-based component. That should not change whether or not you're at the household design structure. So if you're asking a person on the web or by phone or in person or using a piece of paper, they will be responding, for example, for everybody in the house.

>> Oh, I'm comparing an individual to the CPS. So these are individual respondents.

ERIC LAUER: So I think, for example, what you would want to do is compare people who are responding for themselves in your web-based survey to people who are responding for themselves in the CPS to start?

>> It's still really high.

KIMBERLY PHILLIPS: I can say that for us, I don't think that the prevalence was that high. I don't have the figures, though, from the random digit dial right off the top of my head but we can connect about that.

>> But didn't you just look at people with disabilities?

KIMBERLY PHILLIPS: Yes, but we started with the health conditions panel, so we knew everyone even starting our survey were reporting some type of health condition. It was very broad. But I think 11,000 people began our survey in order for 3,000 to make it through our disability screeners. So it wasn't that high.

At the same time, I would say that it's really important to use specific types of sample checks. So attention checks and where, you know, you put in some dummy questions to make sure people are responding attentively. You look at how long people take to go through your survey to make sure they're paying attention, and that they're answering to the best of your knowledge truthfully.

And also there's another -- you mentioned what I would call long string responding, having a bunch of yeses at the end. There's another way to check for that to see, and you can drop those people at the get go if you want to.

JESSE CHANDLER: Are you talking about a sample where you're recruiting from an online panel vendor?

>> Actually, I didn't do this. These were surveys that other people have done that I'm just analyzing.

JESSE CHANDLER: There's definitely issues with professional survey respondents. Over time people learn this heuristic that whenever someone is asking you whether you belong to a rare group, you just say yes because it makes you eligible to participate.

My favorite anecdote that speaks to that is in market research panels something like 15% of Americans own Segway personal transporters.

[Laughter]

I think this is really an issue of data collection when you're recruiting rare groups. When you're going after a population that's not particularly common in the population, even a small amount of people who are engaging in sort of bad behavior like that will have a dramatic impact on your estimates and I'm happy to share some papers afterwards with you that's related to this.

DAVID WITTENBURG: So Andrew, we went a little bit long on this question. Do you want me to -- okay. We have one more question or should we wrap up?

ANDREW HOUTENVILLE: Wrap up.

DAVID WITTENBURG: Okay. You can approach at the end.

Thank you, panelists, for the discussion and the audience for being interactive.

[Applause]

[Break]

ANDREW HOUTENVILLE: We have an hour and a half lunch today. I hope you will come back afterwards. I like long lunches so we have a chance to network along the way.

Panel 2, using program and linked data. One of the things as this happens, as RDD, as in-home surveys, became more and more and more expensive and federal budgets in particular became tighter and tighter and tighter, there was this lasting hope that administrative records and program data, say from Social Security or from CMS, Center for Medicaid and Medicare, they would all have their administrative data that would come and save the world. In fact, when it came to program participation, the version of SIPP was redesigned that was going to merge together and really tighten the sample and reduce the size of the survey and add in earnings data and other data from social security and Medicaid and Medicare records. That never took flight. But it's always this promise.

What you're going to see today are three examples of the power of administrative data, not necessarily here as a replacement for survey data, but expanding upon survey data and doing more than survey data can do, particularly with longitudinal, following people over time, which is expensive and has a lot of attrition, but we have VR service program and in particular social security programs and records that follow people over many, many years.

Of course they're not without measurement error, but you guys will talk about that.

I'll introduce my colleague from the UNH, Debra Brucker, and she will go first.

DEBRA BRUCKER: Thanks, Andrew. I think I win the prize for longest title of the conference today, although I guess Dave's is quite long as well.

My talk provides an example of how merging administrative data with national level survey data can meet the needs of policymakers at the federal level.

I just want to acknowledge NIDILRR, who supported my work on this project.

As background for this project, we know approximately 13% of the U.S. population lives with some form of disability, and that people with disabilities are more likely to live in poverty, have poor levels of health, have higher rates of healthcare utilization, and participate in public programs such as rental housing assistance compared to people without disabilities.

ANDREW HOUTENVILLE: Dave is getting in the way.

DEBRA BRUCKER: I know. He's too tall.

HUD offers several kinds of housing assistance, multi-family housing, where private poverty owners receive subsidies to provide affordable places to low income people; public housing, where tenants can receive subsidies in specific public housing units; or housing choice vouchers which used to be called section 8 where subsidies are provided directly to tenants who can take them and choose where to live, doesn't have to be within a designated public housing facility, assuming that the property owner agrees to participate and adhere to the program rules, so there is some discrepancy on the parts of the property owners whether or not they will accept these vouchers.

HUD has recently embraced a health in all policies approach, seeking to develop effective policies and programs for residents with disabilities. However, the administrative data doesn't allow them to look at this in detail, so the key research question we tried to answer is whether people with disabilities who exist in HUD housing are more likely to have poor health and healthcare access than other residents.

We know that the measurement of disability within HUD administrative data has limitations.

The data HUD collects has a one question, yes/no, do you have a disability, and there's certain criteria used to determine whether or not someone has a disability, but it's self-reported, and HUD is not exactly clear how this is operationalized at the ground level, so how consistently this data is collected for people with disabilities.

On the other hand, we know national household survey data don't always accurately identify people with disabilities who participate in federally assisted rental housing programs so there are studies that have shown some underreport in national household surveys that try to measure participation in these types of programs.

So the National Center for Health Statistics had a great idea with HUD to merge their administrative data set with the national health interview survey, which would provide more detail about disability, the HUD data would provide more and accurate detail about what types of programs people are in. There's a link provided on this slide that shows you where this data is now publicly available for researchers who are interested in accessing it.

We used pooled health survey data from 2010-1012 with NHIS and HUD administrative data. We used logistic regression to assist the likelihood of poor health status, controlling for disability, housing, and individual statistics.

You've heard about the six questions used this morning. They're also in the national health interviewing survey. We categorized our groups by multifamily, housing voucher, and so on.

We measured many variables, whether people are fair or poor health, hypertension, asthma, diabetes, obesity, whether they were current smokers.

And we also looked at healthcare access, whether people had insurance, had talked with a medical specialist or doctor in the past 12 months, whether they needed but couldn't afford healthcare, and whether they had two or more emergency room visits in the past 12 months.

We controlled for demographic variables, including age, which we broke out into 18-61 and 62 and holder because within HUD, over 62, individuals are eligible for elderly adult housing.

Sex, race, ethnicity, region, and so forth.

So of our sample, 44% of these HUD assisted adults had a disability. 58% were working age. 74% were female. 50% did not work in the last 12 months. 67% were below the official poverty measure. 16% were not covered by health insurance.

The housing assistance program categories were fairly evenly split. Nearly half in public housing.

We did find that adult residents with disabilities were more likely to have fair/poor health status, diabetes, asthma, hypertension, obesity, and to be cigarette smokers. And again, this is compared to other residents, other low income residents in these housing assistance programs. Adult residents with disabilities were more likely to have health insurance and to have accessed care in the past 12 months but also were more likely to not be able to afford the necessary care.

We didn't find any differences by HUD program category, which was something we were interested in examining if we would find people who tended to be healthier or not within various HUD programs and found no differences there.

We found some differences by age. Older adults were more likely to report fair/poor health, diabetes, hypertension, and to have seen a general doctor, but were also less likely to be a smoker or have seen a mental health doctor in the past 12 months.

So this has specific policy implications for HUD. Just the finding itself that 44% of their HUD-assisted rental housing adults have disabilities is higher than the estimates that they've seen just within their administrative data.

And secondly, we find that these adults with disabilities are fairly evenly distributed among the three different types of HUD rental housing assistance programs. There are some specific targeted types of multifamily programs for people with disabilities, but our evidence shows that people reside within all HUD-assisted programs, not just within a disability-specific HUD program.

HUD-assisted adults with disabilities could use more coordination of services to improve health. And there is an ongoing project right now that's being evaluated where they're

testing out offering service coordinators within elderly housing to some multifamily elderly housing residents to help with coordinating their services for health. The thought is if this is shown to be effective, it can be expanded within the portfolio programs that they have.

We also found, as I mentioned, that adult residents with disabilities are more likely to smoke cigarettes. This is of interest to HUD. They recently provided smoke-free guidance in an effort to make all public housing smoke free. They do offer resources to design public housing authorities, owners, and residents in achieving smoke-free environments, which would be relevant to residents with disabilities as well.

So in conclusion, I just wanted to suggest that this is a great way to partner administrative data and survey data to meet the needs of the federal agencies with real concrete policy questions they're trying to answer in terms of developing programs for specific populations.

If you have any questions, you can contact me at my email or phone number or find me during lunch. I would be happy to talk more about this. Thank you.

[Applause]

DAVID MANN: Good morning, everyone. I've already assured my colleague Jesse that this tablet is one of the missing tablets.

[Laughter]

My presentation today will discuss a project that I conducted with my colleague Todd Honeycutt and Michelle Bailey and John O'Neill.

The study was funded by NIDILRR and uses linked data to look at the long term outcomes of VR applicants. The study is forthcoming in a special issue of the Journal of Vocational Rehabilitation.

I'm going to give you've a quick overview of VR, which provides services and supports to people with disabilities who wish to work. The program serves mostly working-age adults, though about a quarter of VR applicants are transitioning youth.

Application for VR services is voluntary. About a third of VR applicants are SSI or SSDI beneficiaries. Although VR is state and local, it is funded federally but administered at the state level.

The Rehabilitation Services Administration, RSA, collects data on the VR program. Their files are reported annually on all VR cases closed within a given year.

The files contain a wide range of information from applicant characteristics at application to VR services received to employment and other statuses at closure.

However, the RSA does have some critical limitations. All available RSA-911 files currently do not report data on folks' closure outcomes, though that will be changing eventually due to WIOA. In addition, the RSA-911 contains limited information on applicants who don't receive services.

I like to think of this file as the hill we can't see over. What happens after case closure is beyond our view.

Fortunately linked data enables us to look over the hill, which is the key contribution of our study here, linking administrative data from various agencies to look at long term VR outcomes.

Our study used linked administrative data to examine applicant outcomes up to seven years after program exit. We looked at three sets of outcomes: Two earnings-based employment measures, SSI and SSDI benefits suspension or termination due to work, and also SSI and SSDI updates, people who are becoming new beneficiaries.

To do this, we estimate regression-adjusted models.

A quick preview of our results, what we see is that outcomes vary by status at closure. And we saw that the poorest outcomes tended to be among those who received services and closed without employment. The best outcomes were those who received services and closed with employment. These comparisons are relative to those who applied for VR services but didn't receive them.

So as I said, we're using linked administrative data here, linking the RSA-911 files to two sources from the Social Security Administration. One is the disability analysis file which contains information on SSI and SSDI benefit receipt, and the master earnings file which contains information on earnings as provided to SSA by the IRS.

So our sample includes all VR cases closed in the 2004-2006 calendar years. That's about just under 1.8 million records. We removed those close to retirement age so we wouldn't have misleading results.

We linked the data across files by social security number. And we accessed the SSA data due to security concerns.

So this table gives you a basic sense of our sample. These are unadjusted descriptive statistics. They're being sorted here by SSI and SSDI benefit receipt status. You'll see as far as the percentage who actually go on to receive VR services, it's a rather narrow 7 percentage point range, but when you look at the employment status outcomes or variables here, whether you're looking at employment status at application or at closure, the time they leave the program, those who are not receiving SSI or SSDI benefits tend to have the highest employment rates followed by SSDI-only beneficiaries. And then those receiving SSI payments whether by themselves or with SSDI benefit payments tend to have the lowest employment rates.

As I said, we look at three sets of outcomes. We have two earnings-based employment measures. One we just call employment. That is earning what is equivalent to a quarter of coverage for SSA benefits. That's about $1,200 a year. It's a relatively low threshold for employment.

The other threshold variable is a more substantial threshold, whether a person earns above the analyzed SGA amount which is about $12,500.

Our two benefit suspension/termination variables are confined to those who are beneficiaries at VR closure. So what percentage go on to spend months in suspension or termination due to work.

This variable is right from the disability analysis file.

New SSI and SSDI benefit receipt. We can file our analysis into those who were not SSI and SSDI at closure but eventually go on to receive these benefits.

Just a quick summary of our methods. In the paper, first we present basic descriptive statistics like the ones I just presented to you, and then we estimated two types of regression models for our binary outcomes. We used logistic regression and negative binomial regression.

And in the slides that I'll be presenting in just a moment, we present the results as odds ratios and incidence rate ratios so the results can be readily interpreted.

And I want to stress that this study is estimating correlations, not causal effects. So what we're saying is someone receiving services and closing with a certain status is correlated with certain types of outcomes, not that one causes one to have a certain type of outcome.

We do actually have in process studies focused on VR for estimating causal program effects, but this study is focused on correlations.

So this graph gives you a sense of the earnings-based employment results. Just to orient you on this figure, you should see the 1.00 line as representing our baseline group or our comparison group, those who applied for VR and didn't receive services. So any number that you see above 1 means a group is more likely to have that result where if you see a number below 1, that group is less likely to have that result.

What you see here across both of our outcomes is that you see that those who close with employment, those who receive services and exited the program employed were most likely to spend an additional year employed.

And then we see the opposite is true for those who received services and exited the program without employment, they are the least likely to experience an additional year of employment.

Moving on to benefit suspension or termination due to work, we see a rather similar pattern across both SSI and SSDI. We see that those who close with employment are by far the most likely to spend an additional month in benefit suspension or termination.

For the other group, those who closed without employment, we see for SSDI, they are the least likely to spend time in termination or benefit suspension, but for SSI we find that those who closed without employment are just as likely as those who didn't receive services to spend time in benefit suspension or termination.

Now, moving on to our SSI and SSDI update. This is where the slide that I think contains our most counterintuitive result. For SSI, it's as one would expect. Those who leave the program without being employed, they are the most likely to go on to receive

SSI payments, whereas those who exit the program with employment are the least likely to go on to receive SSI payments.

However, for SSDI, both groups are more likely than those who don't receive services to go on to receive payments. One would potentially expect this with those who exit the program not employed, but for those who exit the VR program employed, to see them to go on to be more likely to receive SSDI benefits, that was counterintuitive to us.

So some general take away findings of the three figures I just showed you, I think, one is that applicants who do not receive services are a relatively heterogeneous group. We're comparing them to a sample of those who receive services based on whether they exited the program with or without employment. So we're effectively sorting these groups, these individuals, into groups based on the severity of their barriers to employment. And when you're looking at these groups and compare them to the heterogeneous group who didn't receive services, you can see strong differences in their outcomes.

The other general take away I think here is that new benefit receipt varies by program. This speaks to that counterintuitive result for SSDI. Once we saw that result and double checked that the result was right, we tried to figure out, well, what could this be. This is speculative because this is really a correlational study, but the thing -- one idea that I thought it was particularly interesting was the idea that the program rules for SSI and SSDI differ. SSDI coverage is based on being insured for the program. So it could be that some people are receiving VR services, exiting the program employed, are working long enough to become insured and then when their condition worsens and they're not longer able to work, they can apply for SSDI benefits.

So what are the policy implications here? I think that there are two of them. I think one is that it seems that there are opportunities to further target assistance to VR clients, and I think that this is true both for those who close with and without employment. For those who exit the program not employed, there are opportunities to point them to services and supports that will enable them to be sustained economically for the long term.

And those who exit the program with employment, there are opportunities to provide them with additional supports and services that allow them to continue successfully in the workforce.

The other policy implication that we have is that the findings suggest a possible benefit of VR service receipt via increased resources or in response to poor economic environments.

This is our funding acknowledgment. Again, we thank NIDILRR for their support with our work.

And this is my contact information, my email address. I also tweet on disability-related issues and you can follow me on Twitter if you would like to.

Thank you.

[Applause]

DAVID WITTENBURG: Okay. We keep moving closer and closer to the podium with each discussion.

I'm going to talk about when every dollar counts. I have a long title here, that basically just compares survey responses for earnings and employment to administrative responses for earnings and employment. So it's a fairly simple concept. We have two outcomes measured in two different data sources and we want to see how they compare.

This is work that I did with my coauthors Holly Matulewicz, Jeffrey Hemmeter, and Lisa Schwartz. This is work that was both beneficial to Social Security Administration in terms of thinking about how to develop their own surveys for demonstration projects, as well as broader projects, but also for NIDILRR in terms of informing about surveys more broadly for people with disabilities.

So the punch line here is that when we compare administrative and survey data estimates, what we're trying to show here with this chess piece, I realize that the crowd responds much better to kids playing with data than these chess pieces, but my kids play chess so I'll go with this.

The basic finding is that employment and earnings rates are consistently higher in administrative data relative to survey data. We find that employment rates of SSDI beneficiaries, the population that David was just talking about, was 19.2% in administrative records compared to 13.6 for employment rates based on just survey responses.

So a couple impressions from this. Why does this matter? First of all, if you're looking at broad employment trends and broad employment estimates, the survey and the admin data actually do a pretty reasonable job approximating each other. They're both below 20%. We find the majority of beneficiaries are not working.

However, when you start digging deeper into the beneficiary population that works, and remember, this is a population that policymakers particularly Congress cares a lot about. When you think about these new demonstration projects, like the benefit off set national demonstration project, they care about who is working, getting more precise into that population matters a lot and understanding who works and who is responding versus who doesn't respond is equally important.

And if you want a practical example of this, consider a simple example of if you're trying to do a screener if you're SSA and identify a work pace sample, what's going to happen based on these results, you're going to underreport.

That's why these findings are important.

So what was the policy and research by social security? The things I just mentioned. First of all, they want to develop policies and demonstrations. It's not just thinking about survey projects for these big large demonstration projects, but it's also thinking about the Ticket to Work program. How do we send outreach fliers to ticket participants to maximize response rates? How do we reach the right population with the right resources?

These are very, very important services from a policy standpoint.

From a research standpoint, this is where my survey design colleagues are very, very important. When you think about employment and earnings questions in surveys, they tend to be quite long. And one of the reasons that they're long is because when you're trying to track annual employment and annual earnings, you have to go back and figure out when jobs start, when they end, how much of their earnings there were. So there's a lot of what I call survey real estate devoted to figuring out what annual employment and earnings is.

There's also an important survey design question in terms of who responds, who is most likely to respond.

So we weren't the first to do this. But we were the first to use Social Security administrative records to compare employment and outcomes across the survey and administrative data sources but there is well established literature that has looked at the current population survey and program participation comparing income sources in those records to the administrative data sources from unemployment insurance records.

A lot of interesting findings. One that parallels with our findings is that, yes, administrative data tends to show higher numbers. The problem is, when you look at those surveys, they have a much harder time digging down into specific subgroups of beneficiaries such as disability beneficiaries that are much less likely to report employment and earnings.

So our research questions are what are the SSDI and SSI employment rates and earnings, do the levels differ between survey and admin data, and do the demographic subgroups differ between the overall population.

In terms of the survey, we used the national beneficiary survey. Deb is in the audience; she directed this survey for years. What's unique about the national beneficiary survey is it's a nationally representative sample of all disability beneficiaries, including all the DI and all the SSI beneficiaries.

What we do is we select a sample of working age beneficiaries between 21-64 at the time of interview. And for the purpose of this presentation I'm only going to focus on DI beneficiaries, which I define to include those who receive just DI as well as those who receive DI and SSI.

We pooled data from three panel years of the NBS. 2004-2006. And we have approximately 8,000 observations for sample members.

We compared the survey responses and link them to the master earnings file. For the MEF, these are the data file that SSA maintains, including annual earnings data compiled from the IRS and they're drawn from the forms W-2 annual tax forms, defined as maximum social security taxable wages and self-employment earnings of Medicare taxable wages. They provide really an automated source of employment and earnings. That's the key to the admin data.

In terms of the population, we're working with a sample of disability insurance beneficiaries. This sample tends to be older. They also tend to be split between male

and female. Approximately 75% of our sample receives DI-only benefits, whereas 25% receive DI and concurrent. If you want to simplify that, 25% of our sample is low income, given that you have to qualify for a means test to qualify for SSI.

In terms of actual responses, interesting was how many people respond on their own. 80% self-respond. Approximately 18% use a proxy. The majority of the population is older. I think my coauthor said 82% are over age 40 as defining older, which made me worry given she's under 40, so I'm now old.

So this slide I think really is the punch line to the presentation, because if you compare the left-hand side, this is the master earnings file. We aggregate employment and earnings at a single measure. To construct that same annual employment and earnings measure for national beneficiary, you have to look at the month and the year, the start and stop, look at the usual numbers of hours and week work and rate and frequency of pay, and make certain assumptions to calculate the annual earnings rate.

This is important. If you think about this, think about the real estate that takes up in surveys and think about the conversations we've had this morning about web-based surveys.

Key findings. Administrative data are consistently higher across every single subgroup we look at in the analysis. For the overall sample, 19.2% employment rate compared to 13.6% in the survey self-reported responses. If you're looking at a proportional difference, relative rate, that's a 41% difference.

DI beneficiaries have slightly higher proportionate differences relative to concurrent beneficiaries.

I'm going to move now to age because age I think is a particularly compelling finding. And what you see here when you compare the dark blue lines to the light blue lines is approximately the size of the gap is pretty consistent across all age groups. There's about a 4-6 percentage point difference in all age groups, which you may say seems pretty consistent. But it's actually not when you think about the proportional differences. When you start thinking about older workers, particularly that group in the 50-59 and 60-64 range, in admin data you get 15% who report employment as opposed to 8%. So the rates are nearly double in the administrative records. So these are very, very big proportionate differences even though the aggregate differences by group matters.

So key finding two. Now we're breaking down moving from the concept of employment to earnings, and what we find is that the earnings levels of all beneficiaries are relatively low. The average earnings is $1,125 annually. That's because there's a lot of DI beneficiaries who don't work.

If you look at the survey data, the light blue mark, it's $514, 118% proportionate difference. So there's an even bigger gap between earnings and employment.

The proportionate differences are larger for DI only, where there are higher earnings, and smaller for concurrent. If you think back to the previous slide, concurrent had higher employment rates. This will be a consistent theme throughout the findings. The higher the employment rates of the group, the lower the disproportionate part of

earnings. Or, if you can remember that you're reporting employment, you'll get closer to the admin records. So recall plays an important part here.

Same graph as before, same point as before. Huge differences at the older age range in average aggregate earnings between the dark blue lines. $886 versus $289 for 50-59-year-olds.

And similarly for proxy respondents, we see pretty large differences but not wild differences between proxies and unproxies. So good new here is that proxies seem to do a pretty good job as self-reports in reporting earnings. We didn't see large differences between the two groups.

So then we said, okay, well let's take a look at people that are employed in both administrative and survey data and restrict our analysis. If you say you're employed in both data, what are the average earnings and what do they look like, do they become closer.

Perhaps not surprisingly, you do. On average for those who have earnings, the average earnings of DI beneficiaries is $6,402 in the administrative records compared with $4,181. The difference is much smaller proportionally. So once you can remember you had employment, these large differences really matter.

So what are the factors driving the results? I list these in order, but recall issue is one of the things that I speculate is the fact that is the biggest driver here because what we consistently find is for these low employment groups, these older workers, that there tends to be -- these are probably the workers that are cycling in and out of the workforce, being interviewed in November but may have worked in March and they may not recall that information.

These are the groups where the proportionate differences really matter. This tells us something I think about designing survey questions and using admin data.

But there are other factors, which are differences in types of jobs held and for the national beneficiary survey, when you're recording earnings, we talked about mode effects earlier today. Beneficiaries responding to SSA may be a little more cautious about reporting their employment earnings.

So what is the summary? I think that these findings have important implications for researchers and policymakers. Administrative data produce higher employment earnings rates than the surveys, and the largest differences are subgroups are relatively lower employment rates. From a policy and research standpoint, from survey design, I think when you are considering having linked data and you're considering these tradeoffs, particularly some of the things we're talking about this morning with web-based data collection and different what I would call cheaper forms of web-based data collection, there's a lot of real estate you can put on these forms in terms of the questions. You have more flexibility on a phone interview to ask longer questions, but as we continue to evolve, I think we're going to have to continue to make tough choices in terms of what goes in to some of these surveys, particularly if there are options to link administrative data.

And finally, I think that these findings are important as we consider targeting efforts for demonstration services, that if we have to use screeners, knowing in advance that there are certain populations that we might miss and how can we use the information like predictive models to better identify these populations.

So this is a picture of me.

[Laughter]

And that's my address. And these are all the agencies we worked with. We're very grateful to both SSA and NIDILRR, NIDILRR for the funding and SSA for access to the data source.

And our formal thanks for the EDGAR notes.

Thank you very much.

[Applause]

ANDREW HOUTENVILLE: Great. We have some time for questions. The mics can be passed around.

>> Thank you for covering this very important topic.

I noticed that the data was off. To me, it looked like the outcome of the data was moving. Is there a way we can get more current data or is there another way we can do it?

DAVID WITTENBURG: You're looking for can we generate information on a more updated, more recent basis, using admin data because the concern is that if you look at my paper, for example, the data are from 2004-2006. Do I have your question right.

I think the answer is yes. I think one of the reasons we had data from that period, that's why we selected it. When you think about studies like this that use survey and linked administrative data, where you have to go and clean the data, those types of studies take a much longer time to develop than some of the studies that you saw this morning where you can build in the responses. So say you wanted a much quicker response rate. You look at the survey employment on disability, what you can do is you have administrative data on VR applicants and you design a web-based survey and particularly if you set it up well, if you can get a VR panel, you can get very quick rich information quicker, but there's a cost to that. It's a very specific panel and you have to be very, very precise in what you're asking the data to do. But if you are very precise in asking your research questions, you can get data much, much quicker. So thanks.

>> Hi. My question is primarily on self-employment. So as you were looking at employment for several of the studies that you mentioned, is there any difference or distinction between traditional employment versus self-employment? Because I think that is a really interesting avenue, especially with this new shared economy with YouTube and Airbnb and all those kinds of things. They can be forms of employment that might not be registered by some agencies. So I'm just wondering where self-employment plays into this whole piece.

DAVID WITTENBURG: Yes. It's a very good question on self-employment. We do have data in the paper, and I'm not recalling what the answer is off the top of my head about how survey self-response for self-employment compares to the admin data.

But the admin data do include information on self-employment data because they're essentially are FICA tax records so we are picking up those groups.

To your point, I think it is a really important question to ask because people with disabilities are more likely to be self-employed, to pick up the smaller industries.

If I were to speculate on your answer, I would suspect that the self-employment measures of employment are probably pretty accurate because if you start your own business, you're likely to remember it and track your employment earnings pretty well.

ANDREW HOUTENVILLE: I don't know about that. It depends on the size. If I'm doing consulting, sometimes I don't remember that I earned something last year. So I actually wanted to follow up with that. The earnings for the older ages, they also had lower earnings to start with. So they may have more sporadic employment and may not be remembering. If you're self-employed but you started three businesses and you've had three different contracts, it's more sporadic. The recall error may be more because you have more to remember.

DAVID WITTENBURG:

Well, that's actually kind of the main gist from this. The more volatile the employment, the less likely the survey measure is going to pick it up. So if the question is if you have sporadic self-employment, the measures may not be as good as stable self-employment.

DAVID MANN: Even though the study I presented today doesn't look at self-employment separate in other types of employment, we have a NIDILRR funded study going on right now looking at outcomes of VR applicants based on their status, their employment status, at application. And one of the groups that we look at is the self-employed group. So look for that in the coming months.

ANDREW HOUTENVILLE: I see three hands back there.

>> On the note of self-employment and -- hi, I'm Anupa with EEOC.

On Diego's point around self-employment and a lot of this merging employment opportunities through social media, etc., I mean, that employment data would be quite recent considering that this sort of growing web or independent contractor jobs have been starting in the past, you know, 2-3 years in terms of growth. So are the studies that you will be doing, will that be kind of looking at more recent W-2 data or how is that being parsed out?

DAVID MANN: In the study we're doing currently, we are only relying on the RSA-911 files for outcome. So we're looking -- it would be great if we could link administrative data like we did in this study, but for this ongoing study, we're unable to do that and we have to focus on what outcomes we can observe in the RSA-911 files. So what we're looking at is our individuals with certain employment statuses at application, are they

ending up receives services from VR, and if so, are they exiting the program with employment.

Not only do we look across different employment statuses but we also produce agency by agency estimates. So for those of you in the crowd with particular VR agencies, you'll be able to look into the paper and see how your agency is doing.

ANDREW HOUTENVILLE: Just another way of answering that question, not with the studies that were presented, but the Bureau of Labor Statistics, BLS, and the North American industry and also the occupational codes, they're having a hard time keeping up with new types of jobs. You know, so if you look at the most rapidly growing industries or the most rapidly growing occupations, you won't see the words you're using. You know, you'll see I.T. You'll see information systems. And so part of it is an evolutionary issue, that some of the information you're asking just hasn't yet been developed.

>> Well, my follow-up question was actually how do you define employment in these surveys so that it could capture that type of data?

ANDREW HOUTENVILLE: Yeah, that would probably go towards the occupational coding. I'm not sure if the 911 or if any of the social security files have occupational codes. IRS data does not come with occupational codes.

DAVID WITTENBURG:

Yeah, they don't drill down into the type of employment.

ANDREW HOUTENVILLE: American Community Survey would probably be the best because of the three digit industry codes. There's people from ODEP they sponsored years ago, and I think EEOC was part of that, to get better occupational-level data. But again, those categories are probably developed in 1990 and may not reflect some of the groupings that you see.

DAVID MANN:

The RSA-911, just to finish, has about 12 statuses that they have reported as far as status of application.

And then we aggregate those up to a certain extent to create our measures.

>> Daniel Davis with Administration for Community Living.

My question involves the housing study and specifically that 44% number is very striking in light of frankly the lack of accessible housing even in public housing, the 504 regs are relatively modest in their goals.

I'm wondering your thoughts for the implications for both housing programs as well as building design and management.

DEBRA BRUCKER: I think it's positive that HUD has noticed this gap and are working to add in information from national-level household surveys to improve the information that they have about people with disabilities.

As I mentioned, they have a demonstration going on right now trying to figure out how to better serve populations that might have health limitations within their housing portfolio. You know, my two coauthors are from HUD on this paper, so they're obviously very invested and interested in distributing the results in hoping that the policymakers within their institution pay attention to this as we get these results published.

ANDREW HOUTENVILLE: Deb, is it possible, when you break down -- the thing you did show that's kind of related is that the three programs didn't have anything different.

DEBRA BRUCKER:

Regarding the health, not outcomes but health status.

ANDREW HOUTENVILLE: There's other kind of community living or community engagement that you could -- because those have to be different accessibility wise, you know, because you would think that the programs, the facilities would be differently accessible.

DEBRA BRUCKER:

Right. So for people that have the housing choice vouchers, they can go rent housing anywhere, whether that's a freestanding house or an apartment or, you know, they can sort of search for something that might meet their accessibility needs better than a public housing facility that is built in pretty standard but needs to be modified. There are long wait lists for all of these programs and limited resources, because there's a definite need. So more collaboration. I can't speak for HUD directly, but...

ANDREW HOUTENVILLE: What time are we at? More questions?

>> Carol Boyer from the Office of Disability Employment Policy. First of all, I'm looking forward to the article coming out in JVR.

And I wanted to make a comment about more people with disabilities are more likely to be smokers in general but especially in public assisted housing, and I'm wondering if those of you who are researchers correlate that with the advice childhood experiences study. Kaiser Permanente Foundation CDC longitudinal study that shows people are more likely to be drug users and chain smokers and other behavior that's not good for your health if they had traumatic experiences before the age of 18, which I thought it was an interesting statistic.

DEBRA BRUCKER: Thank you for sharing that. I'm not familiar with that study, but I would be interested to look at it.

>> Thank you all for your presentations. They've all been interesting.

I'm Kirsten Row and I have a question for David Mann and then all of you.

David, I'm going on a thought you mentioned about the retrospective nature of this kind of study of administrative data, always having to look backwards. Given that VR has increasingly been focused on transition-age youth, I think the statistic you quoted was about a quarter of people were that age. In Virginia, it's 50% now.

What do you think the implications might be of the results, if we're looking forward, especially in implementation of WIOA and the requirement to serve transition-age youth?

And secondly, more broadly, what potential do any of you see for making use of longitudinal data using linked administrative records from the state longitudinal data systems? I know VR hasn't been a major partner in many states but there are an increasing number of states that do include VR data in those state systems. Certainly in Virginia it's a rich source of information. Lots of depth to the data. I wonder if you see any potential research using those data systems.

DAVID MANN: To answer your first question, I would think hopefully the story for transition-age youth will be similar to that of the general population that we see in our study. That as we see people going through the VR system, receiving services, exiting the program, with employment or without, that we're seeing it providing a strong signal to overcome their barriers to employment and that there are potential opportunities to follow up with those individuals based on their status at that time. I mean, I don't -- in the study, I believe we do control for age, so I would have to go back in the study and see if there's anything more specific about transition-age youth that we could learn. The study is going to be available publicly in a few weeks, so you would be able to do that too soon enough.

DAVID WITTENBURG:

In terms of your second question, I'm hoping in our next data, the science conference, that we will have a whole panel devoted to this in terms of its potential of where I would like it to go.

We're not quite there yet. I mean, I think we've got some states, Virginia being one, the state of California, David Mann has been doing some work with Rhode Island. And so states are developing some emerging data sources, and different states are doing different things. So the promise here is that I think many of the things that we think about in terms of early intervention, particularly the coordination across fragmented systems, really rely on the coordination of data systems coming together.

But this has also been our biggest barrier I think to innovation, is the fact that the data systems have been sitting in silos.

So in some senses, I see both a barrier and an opportunity here to the extent that states like Virginia are working on linking data and they're creating outcome measures, particularly if they feed into WIOA, and those performance measures as I understand it are fairly young at this point and will continue to emerge, but to the point that you can get them to beyond agency thing, to cross agency records, that I think is where the next step needs to go. But there's a whole bunch of security data use agreements that stand in the way. So where I would suggest is to take a look at the case studies where many is working, the places like Virginia, the places like California, to see what they've done, to see if we can create templates in other states. And that will allow us to build the state database systems. To the extent we can build them, you have these efforts going on at the federal level, the National Commission on Evidence-Based Policy Making is

considering the development of a federal database. I think to the extent that states are well positioned to be able to link to that federal database, the further that they will be ahead on this.

I wish I could provide more specifics other than hope, but the only specifics I would say is for states that are doing this, share the game plan with the states that are not and see if you can develop more pilot studies and pilot states because once the data becomes used, it becomes important and can be useful for evidence based policy making.

DAVID MANN: I just wanted to hop on that comment and add that you would think you're making this point at the end, Dave, that it's not just about linking data; it's about empowering the states to be able to use those data. My experience is on the Pennsylvania rehabilitation council, they've suggested to me that there's a learning curve that agencies are experiencing right now. Some are farther ahead than others, but they have this administrative data at their fingertips where they can really use it to innovate and to assess their program and assess changes and see where improvements can be made. And I think that it's encouraging to see agencies kind of realizing this and see the power of the data that they have and then I think one of the next steps is then to go on and say, how can we link our data to other data sources within the state to better understand our program and ways to improve it.

ANDREW HOUTENVILLE:

Thank you.

I think that's the last question. I would just say that, just to follow up on their two comments, the idea of using state data to look at it provides, as Dave said, well one of the Davids said, one opportunity but also kind of confusion because it's not the same across other states. Similar things happen with the evaluators network for VR trying to harmonize efforts and learn from each other about data collection. There are folks also here from CDC trying to harmonize the medical claims data particularly around people with intellectual and developmental disabilities.

So a lot takes coordination and communities to grow up. I haven't heard about the longitudinal files for youth in a while, and I would be interested to see what's happening there because it never really took off, at least with transition-age youth with disability.

All right. Thank you for a great panel. If you have other questions --

[Applause]

 -- we have an hour and a half for lunch so feel free to approach the panelists if you have further questions. Thank you.

[Lunch]

ANDREW HOUTENVILLE: All right. If we can get everybody to come in and be seated, I'm going to turn it over to the moderator for the next panel.

AMANDA REICHARD:

Good afternoon. I'm really excited to be the moderator for this panel. It's going to be really interesting.

The subject of discussion today is how we can use data to inform policymakers, and I think there are quite a few of us in the room that are on one end or the other of that so hopefully you will enjoy it well.

Dr. Amanda Botticello is here from the Kessler Foundation, and she's going to talk about the American disability guide.

AMANDA BOTTICELLO: Thank you. It's great to be here, and I'm very excited to talk about work that Kessler Foundation is doing in collaboration with UNH, in particular my colleagues Andrew Houtenville and John O'Neill.

Doing work to actually map the prevalence of disability in the United States.

So jumping right in, in terms of what exactly we mean by the disability belt, we're referring to the geographic clustering of areas with a high prevalence of disability.

Now, this isn't something that's necessarily new. In fact, in the last several decades, it's been noted throughout the literature, that there tend to be high disability prevalence areas. By that I mean usually county-level data of contiguous clusters of places such as Appalachia, the lower Mississippi valley, the southeast coastal plains, and large sections of Missouri and Oklahoma that have high prevalence of disability and tend to visually follow this area together.

These areas generally overlap with areas that also have high reported concentrations of chronic health conditions as well as poverty.

Understanding this is important to us because area characteristics, in particular the demographic distribution of the population, the distribution of social characteristics, the physical environment in terms of both the topography, the natural conditions of the environment and built or manmade characteristics, as well as institutional and policy-based characteristics are all things that affect the reporting of disability prevalence.

Evidence of clustering of high areas of disability prevalence, then, can be used by state and local health agencies when we identify them for these agencies to better target policy and health interventions to these high risk areas.

So as I said, this is something that people have been looking at over the years, but in the past, the data has been largely limited, and that's because prior analyses have mostly been descriptive and visual. So for a number of years, we've been able to map disability prevalence, but we really need to understand and actually affirm these relationships statistically, in particular by identifying these high risk clusters with spatial statistics which become more accessible for use with large data.

Information in the prior literature is also based on singular data sources. For instance, much of what we know about the existing disability belt is based on labor market participation data, but as some of our colleagues described this morning, we also have broader based survey data that offers a wider perspective on the general experience of

self-reported disability as well as differences by disability type. So we can map that along with labor market participation.

And finally, the focus in prior literature has largely been on high prevalence areas. In other words, identifying clusters of high disability prevalence that really signify high risk when, in fact, sometimes it's the areas of low prevalence and low risk that are similarly important so we can identify inverse factors that may not necessarily be needed to target interventions but may inform the development of interventions because we can see what other areas, for lack of a better way of putting it, are doing correctly.

So we assessed three very general research questions in this project. Overall we want to see what does the prevalence of disability look like geographically in the U.S. across different data sources and different disability types.

We want to confirm statistically if the spatial clustering of disability is significant and where they're located.

And finally, we want to identify contextual factors associated with geographic variation in distribution of disability. We looked at socioeconomic predictors as well as disability type for this one.

So the analytic approach followed the questions in three basic ways. The first was very simple. We wanted to visualize disability prevalence. So this involved creating a map using survey and GIS data.

The second step was to affirm spatial clustering. This was looking to detect areas with significant concentrations of reported disability. We do this with two statistics. First is the one that tells us if there's a high cluster overall, and second one tells us if it's significant, in other words, if we have high clusters of disability, do these counties with high rates tend to be located in close proximity to other counties with high rates and are they influencing one another.

And finally, to look at contextual factors, we conducted a lagged spatial regression, so modeling this dependence because spatial autocorrelation means that these observations are not random. So modeling this along with what we think are certain poverty and socioeconomic indicators related to disability.

So to do this, we drew on two sources of data. I'm not going to go into tremendous detail because they probably are very familiar to this audience and were described very eloquently this morning. We used disability collected from the American Community Survey as well as the Social Security Administration to create our maps and to also look at area characteristics. We drew from GIS and spatial data using census TIGERLINE files available publicly.

And we also used the ACS pooled five-year sample and median household income, percent unemployed, the percent of houses receiving public assistance, and education level. So looking at the proportion of the county where the highest attained education level was high school diploma.

All data was from 2010. This is a county-level analysis. We looked at over 3,000 counties in the 48 contiguous United States. Alaska and Hawaii would necessitate a

separate approach and they're actually not spatially joined to the rest of the United States, so they cannot be analyzed with this method.

And finally, all analyses were conducted using the GeoDa software available online publicly.

We took the American Community Survey, we used the six self-reported questions, and we created an overall percent of persons of working age who are disabled by taking the number of people who reported at least one disability and dividing it by the total working age population for that county.

Similarly, with the Social Security Administration data, we were looking at SSDI recipients. So this is basically the number of people in the county who are of working age who are no longer able to work due to disability and we calculated an overall percent.

This is the general distribution. There's a higher mean percentage of people reporting disability based on the self-reported survey questions, so about 13%, which is what you would expect given the difference between the way the data is collected and the types of requirements necessary to receive SSDI disability.

Here's also the distributions of each disability type by county level.

All right. So in terms of mapping the overall presence of disability based on self-reported disability in the ACS, here is a general map of the quantiles. The darker areas, the darker the area signifies the higher disability prevalence. So based on the ACS, we can see, as we would expect, areas of the southeast, Appalachia, and the lower Midwest have the highest rates of disability prevalence, as well as areas of the Pacific northwest, Nevada, and New Mexico, and upper Maine.

We can see how this corresponds with the SSDI quantiles. Across the two data sources, we have a similar clustering of high prevalence of disability. This is disability claims data, but we see the darkest areas of the U.S. map are typically along the lines of Appalachia, areas of the southeast, lower Midwest, as well as upper Maine, and a little bit of northern California.

So this is visually what disability prevalence looks like. But what does it mean in terms of is this statistically significant. So the Moran's I score is a measure of autocorrelation. If you're familiar with autocorrelation, this is on a scale of negative 1 to positive 1. What we see is that for the SSDI disability, we have a high level of clustering. This is significant and it's close to 1. So it means that areas with high levels of disability prevalence clustered very closely together.

We observed the same thing for ACS disability. It's a little bit lower, but the data is a little bit more diffuse.

So is this spatial clustering significant, and by that what I mean is locally, areas with high level disability, or counties with high disability prevalence, are they more likely to be adjacent to other areas of high disability prevalence, and similarly with low disability prevalence.

What you see here identified hotspots and cool spots. Interestingly, I applied a more gin gent level of statistical significance given that we have over 3,000 counties and this is a more rigorous approach to the data.

In line with our expectations, we see hotspots for high disability prevalence in the ACS are still concentrated in Appalachia as well as areas of Missouri, Arkansas, and Oklahoma, as well as areas of New Mexico.

In terms of low disability prevalence, we see cool spot as long the northwest corridor, California, and then large areas of the upper Midwest and mountain regions.

How does this correspond with SSDI disability. Well, we see this largely follows along the same area, applying the same sorts of statistical considerations.

Okay. And finally, how does this relate to area socioeconomic characteristics. What we find is as we would expect. With the higher median household income in the county actually predicts lower disability prevalence across both surveys, although the effect is a little bit stronger for the ACS.

Similarly with public assistance, prevalence goes up as it does. And if you have a higher proportion of residents of the county where the highest level of education attained is high school degree, you're more likely to have a higher level of disability prevalence.

The results of the lagged spatial regression were also conducted for each disability type and follow the same general patterns we see with the overall aggregate levels of disability. In other words, there's a negative relationship between median household income and each disability type, a positive relationship between area employment and disability type, public assistance, and high school education across most if not all of the disability types.

And finally, as a last step in this analysis, we wanted to see how well ACS disability correlated with disability claims data. And what we find is that there is a positive and significant relationship of modest effect size. So if the overall prevalence of self-reported disability is high, it predicts a correspondingly high rate of disability claims. And this is pretty consistent across each disability type, although we see with cognitive and mobility disability, the relationship is a bit stronger, and strongest with the self-care and independent living disability types.

And each of these models is adjusted for median household income, public assistance, unemployment, and education.

Okay. So to summarize, the maps of disability prevalence were largely consistent with our expectations. We found a similar array of clusters in geographic variation in the ACS and SSDI data. And more importantly, the spatial statistics confirmed that significant geographic clustering was evident across both data sources and by disability type.

So both data sources showed significantly high clusters in Appalachia, Missouri, Oklahoma, and Michigan, and missing on this list is New Mexico, which was more evident in the ACS data. And finally we saw similarly low concentrations of disability

both self-reported and claims in the New York metro area, along the California coast, as well as in wide areas of the Midwest and mountain states.

Finally, we found that disability prevalence was very consistently correlated with indicators of low socioeconomic status across both data types.

We are finishing up this analysis. One of the next things is to determine if additional factors are related to this spatial variation in disability and disability types. We're specifically looking at certain demographic and social predictors as well as indicators of industrial mix.

And finally, we want to drill down and examine differences in spatial variation by region.

I'm happy to answer any questions at the end of this session, or you can email me. I am remiss in that I did not add an acknowledge slide, but this study was supported by the Statistics RRTC through NIDILRR as well as the Kessler Foundation.

Thank you.

[Applause]

AMANDA REICHARD: Next we have John O'Neill from the Kessler Foundation and Andrew Houtenville from UNH. They're going to discuss the nTIDE trends.

>> John O'Neill in the house!

[Laughter]

JOHN O'NEILL: Good afternoon, everyone. Andrew and I are going to be tag teaming a little bit today. I'm going to start with the basics.

I'm going to be reporting on our experience with producing the national trends in disability employment, which we've been doing since 2003 I think. '13, rather.

It's been a very interesting experience, to say the least.

Attribution. This effort is funded by NIDILRR to a grant to the University of New Hampshire. The rehabilitation research and training center on employment policy and measure.

The monthly nTIDE report. It is a press release, and an info graphic, looking at the latest employment statistics. We used the date from the jobs report that is released by the U.S. Bureau of Labor Statistics on the first Friday of each month. It is a joint effort between the Kessler Foundation and UNH.

The source. As I mentioned, it's the U.S. Bureau of Labor Statistics, the current population survey. It's the official source for the unemployment rate. And it covers civilians ages 16-64 not living in institutions. This information has been available since 2008 onward, since September 2008 onward.

It is not seasonally, not yet, adjusted, yet we hope to be doing something on that soon.

ANDREW HOUTENVILLE: Right, Andrew?

JOHN O'NEILL: Which is why we compare the month that we're looking at to the same month last year.

Measures. We look at the employment to population ratio, number of people working divided by the number of people in the population.

We look at the labor force participation rate, the number of people looking or working divided by the number of people in the population.

We also look at percent change in both metrics. The employment to population ratio and the labor force participation rate. Essentially we take the percent of people working and in the month last year we subtract the percent of people working in the month this year, and then we divide by the percent of people working in the month last year.

We do that for both the employment to population ratio and the labor force participation rate.

Unemployment rate. Number of people not working but actively looking for work, which is divided by the number of people in the labor force. We do not use the unemployment rate because people with disabilities may be disproportionately discouraged and thus inactive. Also the sample size of people with disabilities in the labor force is small to begin with, and if you look at those who are looking, it's going to be even smaller.

I'm going to be reviewing several tables and graphs, Andrew and I will. I'll take the first couple. And then Andrew is going to report out on the last graph that we have.

The first table is a look at the employment to population ratio over from 2009-2016. So it's looking at employment to population ratio for people with and without disabilities and the labor force participation rate for the same two groups.

If you note, the employment to population ratio has increased for two consecutive years in 2016 and '15. It's increased since we experienced a low in 2014. And the population, employment to population ratio increased from 27% in 2015 to 27.7%, which is up 2.6%, and whereas the employment to population ratio as well as labor force participation rate have increased only -- the increases for people with disabilities have been minimal.

This particular slide shows the percent change in the employment to population ratio over 2016. Each month in 2016. By taking a look at more granular level, this more granular level, we think it yields some interesting observations.

The first three months of 2016 were not positive for people with disabilities. The employment to population ratio decreased an average of 1.6% for people with disabilities whereas those without it had increased 1.1%.

The major shift occurred during the next nine months for people with disabilities. With the ratio increasing an average of 4%.

In contrast, gains were much more modest for people without disabilities in the last three-quarters of 2016. Essentially the employment to population ratio for folks without disabilities only improved .7%. It's obvious that the gains made by people without

disabilities during last nine months of the year were only a fraction of the gains that were made for people with disabilities.

We saw a similar trend in 2015 except for the last three months in 2015 when there was a drop in the percent change in the employment to population ratio.

The next slide I'm going to hand over to Andrew because it begs some questions as to where we are going.

ANDREW HOUTENVILLE: Thank you, John.

So if you're around tomorrow, you'll see this again. It's my favorite graph in the world. We're going to have it put on coffee mugs I think. Once this goes up above 32.7, then we'll make coffee mugs.

What you see is the data was starting to be distributed and collected in 2008. First official numbers came out in September 2008. So that's just after the Great Recession. We had the percentage employed at 73.8. At the Great Recession, we actually, tomorrow I'll talk about before the Great Recession. Actually, I'll go back to the 1980s, but you can still see the fall after -- this is October 2008. The Great Recession really hit February 2008 and August 2008 were the big job loss months for the Great Recession, lots of mass layoffs.

You start seeing this progression downward for both of them. And then you see the slow recovery. So this would be the almost 8 years of the Obama Administration's slow recovery for people without disabilities.

For people with disabilities, you still see a decline at this low point around 23%. And then we've been seeing a slow climb afterwards. And we're now at 28.7%. Still not to the point of September 2008. But we're climbing up.

Now, the big question is, and Andrew who is our doorman and mic guy and Power Point guy, he's doing his master's thesis on this trend. And the big question we have is, is this a new plateau from 2011 to 2016? Are we at a new flat point and this low dip in 2014, was that just an aberration? Or are we seeing a curve upwards? So is this a downward curve and are we bouncing back up, or is this just a low point and an aberration and a new flat point?

There's actually some interesting thoughts about the idea of this flat point where during job loss during recession, and I'll talk about this more tomorrow when I look back to the '80s, is, you know, are people with disabilities losing their jobs and people in this audience have written on the poverty track that social security programs may represent for some people. They get stuck in long term programs as opposed to short term unemployment programs. And is this just a ratcheting down of something we've seen go down for years.

It's really fun. We get together one Friday every month at 8:30 when the website goes live. We scrape it together in 10 minutes now and our quotes are usually in the nTIDE fun banter back and forth. I don't know if it's fun for everybody. I know Penny has fun.

Between' put it out and do the nTIDE luncheon.

That's all I have, John.

JOHN O'NEILL: I would like to comment briefly on the experience of doing the nTIDE. It's sort of a grounded perspective.

When we started to do it, we were all about the facts, right, nothing but the numbers. And we struggled with sort of how to characterize the movement from month to month and across months. I can speak for myself, I get sort of elated when there's improvement and sort of it doesn't feel so good when the employment to population ratio is going down. So that's sort of a grounded experience.

You could ask Andrew what his experience is.

ANDREW HOUTENVILLE: Carol Ann is not here so I can speak freely. She's the communications director at the Kessler Foundation and she wants to use more flowery language and I always have to tamp down her excitement. You know, trending up. Well, trending is a scientific term actually. So we get into a lot of back and forth about that.

How many more minutes do we have to pontificate? Two?

Yeah, but it's been an interesting experience. We've heard a lot from around the country about people who, you know, the timeliness, that this month here's what it is, allows them, gives them more credibility and authority to talk about the programs and issues facing the population of people with disabilities. I mean, we can talk about this going up from a low point in 2014, but the gap is pretty substantial. You know, what you don't see is that this is on two different axes. That gap is actually much higher. I'm cheating by putting them on different axes. The gap is still pretty substantial, so there's a long way to go, and Michael Murray can whoop if you want.

MICHAEL MURRAY: Yeah!

ANDREW HOUTENVILLE: I'll take a yeah.

All right. That's it.

AMANDA REICHARD: Thank you.

[Applause]

All right. Last but not least we have Yonatan Ben-Shalom from MPR. He will be talking about tracking SSDI receipt.

YONATAN BEN-SHALOM: I'll be present something trends that don't jump up and down very often.

So good afternoon. I'm very happy to be here to wrap up this session with a look at whether SSDI beneficiaries are entering the rolls sooner and staying on longer than they did in the past.

This is joint work with David Stapleton, who is not in the room today.

I do want to acknowledge and thank NIDILRR for their support of this work and will note that the contents of this presentation do not necessarily represent their views or those of any other federal agency.

So I think everybody here knows that SSDI has experienced enormous growth in the last 30 years which was led to depletion of the SSDI trust fund. The fairly recent budget deal has addressed the exhaustion in the short term, but there is disagreement on the reasons for SSDI growth that have implications going forward.

And researchers and policymakers are electing to continue this discussion in the coming years as the trust fund is now expected to be exhausted by 2023 if not before.

So the reasons for growth around SSDI rolls have been hard to communicate findings that have been presented by the opposing sides. Some of you may be more familiar with these than others. We have no intent to discredit really great work done by others.

But their findings focus often on current ratios and incidence rates, sometimes ages of students, which are not easy to communicate to the general public and stakeholders.

We're hoping that our findings which focus on trends from birth are easier to follow and hopefully improve our understanding just a bit.

So what is the disagreement here? Steve Goss thinks that the reasons for growth have long been anticipated and understood and are almost entirely explained by changes in the population and economy.

In other words, this has nothing to do with changes in eligibility criteria or their enforcement or economic incentives that lead people to apply for SSDI.

Autor and Duggan has been showing that the most important determine at and why we're seeing an increase in the rolls is that.

Much of the difference between this really has to do with the former focused on total counts and latter focused on prevalence or per capita. And of course each side likes to use the scale that most supports their argument.

So given this background and what we try do is try to document as clearly as we could possibly do the extent to which SSDI growth is independent from changes in labor force demographics. And we do this by providing the first publicly available statistics on the extent to which the most recent cohorts from 1995-1994 and look at trends during their lifetimes and also in the duration of benefit receipt among these beneficiaries, how long they stay on the rolls as of a given age.

Because we focus on cross cohort comparisons, our findings are not influenced by the aging of the population. We often hear about the baby boomers. We're extracting from that by looking at the rate of entry for across cohorts.

We find lifetime receipt of SSDI and Medicare benefits, which SSDI beneficiaries eventually get, is increasing with successive birth cohorts. We find in mean years the lifetime receipt of these benefits has grown even more rapidly. And we often account for something often ignored in this literature which is immigration. We can't do a perfect job on that but we do some adjustment to take that into account.

So we primarily use data by the SSA office of the actuary. We also use CDC mortality data. We basically adjust the size of the birth cohort to account for migration since cohort was age 20. I won't get into the methods here. They're fairly straightforward, and if you have any questions, I'll be happy to answer them later on.

What we see here are the results for men. The estimated percentage of each birth cohort that enters SSDI by age 40. So here what you see is the longest time series we have for entry by age 40 for birth cohorts 1955, 1995, through the birth cohorts of 1974, who turned 40 in 2014, and the gray vertical bar indicates the timing of the Great Recession.

Here for many you see the entry by age 40 decreased slightly in recent years and after we do the immigration adjustment I talked about, we have a somewhat stronger decline compared to the series without that adjustment.

Now, in this slide I add entry by age 45. We see that entry by age 45 increased in the series without but not in the series with adjustment. And we also see a notable uptick after the Great Recession.

Moving on to age 50 and then age 55. We see that for men the estimated percentage of each birth cohort that enters SSDI by these ages increase, applying to both adjust and not adjusted series.

That's the picture for men.

For women, the growth in the percentage of each birth cohort that enters SSDI by age is larger than for men. We already see for the age 40 series. We also see the number of disability insured of the cohort size accounts for the effect of the increase in women entering the labor force and the trends are pretty similar, though somewhat muted.

So growth in the percentage of cohort members entering as of a given age has a positive impact on the years of benefit receipt by that age but there are two other important factors that might affect this. Trends in mortality among entrants. So if people are dying later, they have more years on the roll on average. And as people return to work or get off the rolls, we see them lasting a shorter amount of time on the rolls.

According to SSA data from the late '80s and 1997, the annual recovery rates haven't changed much. However, there is a very significant trend downward in mortality rates.

A good thing, right?

So there's a clear downward trend, but we also can see structural shifts in 1982 and 1996. For these age groups you see here, among people who are on SSDI, what is the mortality rate and trends are clearly downward.

What happened in the '90s is that there were reforms to eligibility that increased the number of continuing disability reviews, and that resulted in current beneficiaries having more severe disabilities on average than currently and that is related to the jump we see in mortality in the early '80s.

Many lost benefits after Congress reduces drug and alcohol as conditions, which showed a decline in mortality rates.

On average, you would inspect people to spend more time on the rolls than as of a given age, which is what we look at next.

What we see here is that because of that declining mortality for benefit received as of a given age, there are positive trends. These graphs are steeper than we saw versus the entry because these trends are affected both by younger age and by staying on the rolls longer.

And if we look at that average at age 50, for men it increased by 18% and for women it increased by 50%.

So in sum, we found that successive birth cohorts are entering the rolls at younger ages, as shown here.

And then we also found that growth is larger for men than for women and that these trends largely hold when we adjust for the trend in migration and for disability insured status.

These increases in SSDI as of a given age along with death rates show markedly declining benefit receipt.

So these findings are important policy implications. First, lifetime SSDI and by extension Medicare benefits per beneficiary continue to increase at least through 2014. There are indications of a slowdown and we would want to look at those going forward. But this trend has put pressure on SSDI and the Medicare trust funds.

Second, it appears that advances in medicine are leading to declines in mortality of beneficiaries are not reducing entry. You would think they would move together, right? If we're able to have SSDI beneficiaries on average live longer, you would think that's a trend of population getting healthier and therefore less entry. But on average the folks entering for SSDI for some reason have higher mortality rates and that might be related to the fact that more are entering with low mortality conditions such as musculoskeletal conditions.

And finally, the findings reinforce urgency of testing and adopting policies. People are entering SSDI and staying there for longer. Many of them will be much better off if they were in the labor force and working.

Thank you.

[Applause]

AMANDA REICHARD: So we have a few minutes for questions. Thank you all for your excellent presentations.

Anyone have questions related to data to inform policymakers?

>> Hi, thanks. Laurie Reader from the Census Bureau. I had a question for Amanda. The maps you presented were really striking, and they seemed to also be an overlay of

the general economic climate in our country right now. And I couldn't help but think that there could also be a migration story and a kind of constraint story. Some perhaps individuals without disabilities are leaving areas with poor economic prospects and going to the cold areas, and people with disabilities, even if they have labor force opportunities elsewhere, may be constrained to the area they are because they're tied to state benefits or something.

I didn't know if you had anything in your data that could shed some light on that argument or if you had considered that.

AMANDA BOTTICELLO: In these data, no. It's cross sectional. But it's a good point and another logical step to take. As I mentioned, this concept of the belt has been around for a while and has been analyzed in different ways, and more recently we've had the tools to really delve into it spatially, and I think looking at longitudinal trends would absolutely be the way to go. I can't answer it with this analysis presented here today, but I think you are on the right track. I mean, I think that's probably got a good bit to do with it.

ANDREW HOUTENVILLE:

There might be some retrospective questions on where did you live five years ago. We might be able to use that data to kind of see migration in and out of the hot and cold areas. So that's possible.

There's also a paper by Karen Conway and Jonathan Rocker, my colleague in New Hampshire, who focus mainly on migration of individuals with disabilities over the age of 65. In that case, it's a very different thing. They're actually more mobile a lot of times because they're moving to get supports that they really need.

And sometimes they're moving because they've gone to Florida, they've spent all their money, and now they're moving back with their children and following their children.

So we would want to look at, say, people ages 21-65 which is typically what we're focusing on because there could be very different migration stories for people who are near or over retirement age.

JOHN O'NEILL: This conversation may be begging the question of do we need a longitudinal study on people with disabilities and employment?

ANDREW HOUTENVILLE:

That was really actually the impetus for the one that Jesse presented earlier. You know, the idea of capturing a panel that we could follow over time, because disability coming into a longitudinal, obtaining a disability and entering into a longitudinal file is a pretty rare event still, and that was one of the impetus for work done at Mathematica.

JOHN O'NEILL: I also think, at least as I remember correctly, the new plan at NIH for rehabilitation research across the centers, I remember a comment in there somewhere about us needing a longitudinal survey of people of health-related issues, and it wouldn't be too far of a reach for them to include employment-related and economic issues as well.

>> I have a question. Just a confirmation about, Amanda, you were doing working age, right?

AMANDA BOTTICELLO: Correct, yeah.

>> Okay. The other question is for Andrew. On your graph that you absolutely love, you described it as the difference maybe having a social policy or the reasons this might be happening with the disability rate maybe plateauing or going lower related to policy reasons.

But couldn't it also be this issue of first fired last hired, or persons with disabilities not getting back into the labor force at the same rate?

ANDREW HOUTENVILLE: The evidence around first fired last hired is very weak, actually. I don't necessarily believe that that's the case.

What I would say is that the hypothesis that I would want to test is that people with disabilities either while on the workforce or while entering the workforce have potentially very customized jobs. I think of emeritus professors at universities. It's a very hand-crafted job, right?

And then you get a recession. It's a mass lay off. Everybody gets laid off, not just, okay, you're first out. It's everybody gets laid off. And then it's really hard to find that customized job again and recreate that same story.

Now, I don't know how to tell that with the current data as it exists, but I wouldn't necessarily want it to be called first fired last hired because I think that that puts all of it on labor demand, that firms are making those decisions, and I'm not quite sure that we have any empirical evidence to make that case.

>> My name is Mohammed. I am with Minnesota department of economic development. I would like to ask Amanda about the data. I'm wondering if policy implications are limited to government level or it can be extended to current level too.

AMANDA BOTTICELLO: Just to make sure I understand the question, you're wondering to what extent policy implications at the state and local level could be driving some of this prevalence? Do I have that right?

>> Policy implications can be the county and state level or they are only limited to federal and state level.

AMANDA BOTTICELLO: Oh, I see.

No, I think it has policy implications at all levels. So one of the things we really just touched on in this analysis so far is looking at some of the area-level correlates which are measured at the county level.

So these are fairly large geographic areas, but fairly homogenous in a sense. So I think that further identifying what some of these are along other lines would be more helpful at the county and local level because that's where sort of the localized change can take place. If that answers your question.

>> The county and city government can do.

AMANDA BOTTICELLO: What can the governments do?

>> What the county and city can do.

AMANDA BOTTICELLO: To alter the overall rates of disability prevalence?

Um, I mean, that's a really good question and very complicated. I think in terms of in some of the hotspots that have been identified, you know, it's sort of the million dollar question. These rates have been high for a while. There's a lot of speculation particularly in Appalachia in the south that this is driven by differences in occupation and disability claims. So in terms of improving local employment, I mean, that's definitely something that could be done but is not very easily done.

ANDREW HOUTENVILLE: I would agree. Some of it may be occupational, and I'll say may because I don't have the causal kind of models you would need to make definitive statements.

Occupational safety, a lot of times we see hotspots in places of high agriculture but very specific agriculture. Not like the combines and large mechanized farming of the upper Midwest, but places where people's hands and fingers are in chicken processing plants. In this case, it may be the jobs that create the disability, not the other way around.

And the other thing is, if you look at this, it could be related to risky behavior. Smoking, alcohol use follows similar patterns. The stroke and diabetes belt are basically the same areas.

For me, it ends being an anti-poverty issue and child health and adult public health issue that is really at play. And as an economist, I think it's all poverty and all economics, and of course -- thank you, Susan. And NIDILRR should have technology demographics and economics around that outer circle --

[Laughter]

 -- because economics has a large part to do with risky behavior. And the access to healthcare is largely an economic issue.

So I am just biased though. As another economist, feel free to add.

YONATAN BEN-SHALOM: Another issue prevalent here is opioid misuse. I don't know how far we want to go down that road, but there's things that physicians do that don't necessarily help people stay at work or get off the rolls when they can or, you know, get them down a path where they're really reliant on painkillers and that affects their function and ability to stay in the labor force.

ANDREW HOUTENVILLE:

There is a paper by Joyce Manchester out of Vermont that talks about opioid abuse and potential influence it may have -- may -- on DI and SSI benefits applications among youth. So that may be a wave that's coming at some point.

AMANDA BOTTICELLO: And one other thing I wanted to add sort of related to your question about what can be done at the local level. One of the reasons why I wanted to make the point that I think it would be interesting to also start studying these cold spots is, you know, I went into this analysis with sort of this bias based on the previous literature that we're going to find this rural urban health pattern. But based on some of the results of the analysis, they're in wide areas of North Dakota, Midwest, places that are not urban that have very low rates of both self-reported and disability claims.

So I'm kind of curious. These are areas that probably have similar health access issues as Appalachia but with low rates of disability. And as Andrew said, maybe they don't have the chicken processing plant high risk occupations but there are places that have, you know, for all intents and purposes more manual labor and so forth.

So it would be interesting to see what some of these other correlates are of the low risk areas and see sort of what is going well or what some of the local policies are at the state level.

ANDREW HOUTENVILLE: One more question.

AMANDA REICHARD: Okay. One more question.

ANDREW HOUTENVILLE: And we'll try to make it a fast answer, won't we?

>> This is again about the first study.

One question that I this is I've seen some previous maps which had shown higher concentrations in urban areas as well but it seems like more recent studies have been dismissive of that.

I guess my question is, is there anything to the idea that there might also be some pockets of disability in some inner city urban communities that are also impoverished?

AMANDA BOTTICELLO: No, I would agree. It really depends on the level of analysis. I mean, I'm not sure what exact work you're referencing, but I have some colleagues who have looked at this in Chicago, using census track data. When you're looking at a smaller -- we were looking at the whole nation and using county-level data, so you're really diluting some of that variation you can capture when you look at a municipality or a single state.

So I do think there is something to that. There's definitely pockets of urban poverty and resource deprivation and lack of access to healthcare that have shown up in other studies of geographic variation that I think are just as valid, which is why I think you have to be cautious in drawing conclusions from this because it just really depends on the data and level of analysis used.

>> Thank you.

AMANDA REICHARD: Great. Thank you.

We're going to take a 15-minute break and then reconvene for the final panel of the day.

[Break]

MICHAEL GAMEL-McCORMICK: Good afternoon, everybody. I'm Michael Gamel-McCormick. I'm so happy to be here for this particular panel and to help moderate this panel.

You spent most of this day listening to some magnificent information based on much of the data that has been collected and analyzed.

For somebody who was a practitioner for 35 years in the field, this is my panel. This is what I love. This is about how do we actually take the information that has been collected and put it in the practice at state level, at the association level, at the local level. It's why this information is so critical to have in hand, to collect regularly, and then to make sure it gets pushed out to as many people as possible.

Any time when we're unsure about the veracity of data, this work is so critically important to do. And we're going to have great illustrations in terms of what can actually happen with this data as we move forward.

So I would like to invite up to the podium for the beginning of this session John Connelly from the council of state administrators of vocational rehabilitation to start us off.

John?

JOHN CONNELLY: Well, good afternoon. Thank you, Michael and Andrew. I think you and your team at UNH for this opportunity.

I guess to some degree I'm the fish out of water here. I am not a researcher. I'm an attorney. I've worked in the VR field for 30 years as a general counsel as deputy director and as a director.

So I can my remarks do not necessarily represent best or promising practices.

That's a joke, people.

[Laughter]

You've got to have a little humor, right?

So this afternoon I'm going to be talking about the common performance measures under the Workforce Investment Opportunities Act and the RSA-911.

And I'm going to be speaking primarily from the vocational rehabilitation perspective.

Previously under the Workforce Investment Act, VR was measured by standards and indicators. The slide lists those seven standards and indicators.

They are gone now. They are no longer the measurements by which VR will be assessed or the other core programs in the workforce innovation act.

These were in place for approximately 16 years, so it's somewhat of a big change.

So we're moving and have moved to the common performance measures, and this slide provides information about the statutory and regulatory precedent for that and some of the key things in terms of the common performance measures, which are the terms, the actual indicators themselves, state performance reports which will track performance

under those, the process for establishing the levels of performance under them, and also the fact that there are sanctions in regard to whether these are achieved or reports are not accurate or timely.

This next slide is the actual common performance indicators under WIOA. And if you go back to that second slide, you can see there are major differences in what the standards are at this point.

States do have the opportunity to establish additional indicators. In addition to these, they have to be included in their unified or state plans.

At this point as far as I know there have only been one or two states who have elected to enact additional indicators.

In reporting, states are encouraged to use the quarterly wage record information to measure performance under the indicators. I know there was a discussion earlier today for example about how you measure earnings for those in self-employment. One of the challenges is that those wage records do not have the sum of information about some placements such as self-employment. So agencies are going to have to look for other ways to measure that.

One of the newest measures, and this is one that vocational rehabilitation agencies advocated for and others is a measure concerning the effectiveness of the core programs in serving employers. VR has not had such a measure before, although VR has for a number of years as well as others advocated for what's called the dual customer approach in our program, that our customers are not only individuals with disabilities but also business.

A state has to choose two of the measures of the three. They are listed there. Retention with the same employer in the second and fourth quarters after exit; employer penetration rate; and repeat customer business rate.

The second and third ones that I mentioned I think are probably at this point going to be the favorites among a number of states just because at this point they're easier to track than maybe the first one. That's not an indication of what may be more valuable for particular states; that's really up to the states.

So far in the discussions that we're aware of, it's really been the workforce side of the house that's taken more of the lead in the discussions about which of those two measures to select.

There are some key terms that one needs to be aware of. On this slide there are two, a reportable individual and a program participant.

Program participant is especially important because it's these folks who become part of the denominator for the measures, so these are the ones that are really going to be the focus.

Another key term is when does a person -- when is a person considered to have exited from the program. So those are terms to be aware of when you're looking at the common performance measures.

The RSA-911, this is the report that state agencies were asked to report their data on. The report will now have 392 individual data elements. And at least 100 of these are additional data elements that have come about due to the Workforce Investment Opportunities Act.

Also, previously, this has been an annual report and now we're shifting to a quarterly reporting system which is really something new for vocational rehabilitation and not necessarily new for some of the other core programs.

State agencies will have to begin recording this data on July 1 of this year. Their first report will be due November 15 of this year.

The Rehabilitation Services Administration is really stressing the accuracy of the reporting and also the timeliness of submission of reports. I understand as working on a program to release the state agencies this spring to help them check the accuracy in their reporting.

As indicated in this slide, to be valid, the information for each of the data elements must be collected at the different stages of the VR process such as application, development of the individual plan. It cannot be collected earlier or later.

In calendar year 2016, the education inspector general conducted an audit of three state agencies, looking at the accuracy of their 911 data and found that there were problems or challenges with that data. One of the bases for that is that unlike DOL, RSA has not issued guidance for some time in regard to when things should be recorded, at what point, for example, is an application an application. And RSA is working on developing guidance.

This and the next slide discuss some challenges. The biggest challenge is that states are going to have to modify their data collection systems. And in terms of data collection, that's an administrative expense.

The other challenge, and I guess I'm painfully aware of this, is that somebody is going to have to enter those additional 100 data elements. Probably vocational rehabilitation counselors. And when I was a state agency director, the biggest complaint counselors had with me is, Connelly, why are you making us hit another button! We're here to serve consumers! We can't talk to our consumers if we're entering this data!

That's a challenge. So there is some sort of balance between the data that's to be collected, the return on investment for collecting that data, and who collects it, and the time, and what impact that has on service delivery, and more importantly, the outcomes.

In terms of agency implementation, states are at varying stages. Some are running dual systems right now collecting the old data. Some have already started collecting the new data. And in terms of training staff in regard to these new elements, some have started that training at the beginning of the calendar year, and others are waiting until we get closer to July, looking at an April or May start date for the general training.

So Michael, thank you.

[Applause]

MICHAEL GAMEL-McCORMICK: Thanks, John.

So I'm going to do a public confession here. I was on the team or maybe the Kabul that came up with those 100 additional data elements back in 2013-2014.

[Laughter]

And I'll do a mea culpa right now.

So John, thanks for setting the stage there. David, I think you're up to talk a little bit more about filling in what those data elements mean.

DAVID VANDERGOOT: I will try.

Thank you, Michael. And thank you, Andrew. I know other presenters were very good at giving attributions, but I certainly want to point out Andrew because he signs the checks for us every month, so I'm very grateful to him.

[Laughter]

I want to acknowledge first of although that I've had the great pleasure of working with a group of individuals from the VR program evaluation network. I don't know if any of you have run across these folks before, but these are individuals who are charged with the responsibility within state agencies of fulfilling their program evaluation requirements. And it's amazing that these folks are dealing with all of the challenges that John Connelly already mentioned, and the challenges are huge no doubt.

But there is an element within them that are very excited about what WIOA might be able to bring in terms of new opportunities to learn what works and what doesn't work within the VR system. It's really been a joy to work with them because I know a lot of people are looking at WIOA and the challenges seem to be overwhelming but these folks are looking at these challenges as a real opportunity to find out really what can really be done to improve employment opportunities for people with disabilities, which has really been the mission for a long, long time. So they see it as an opportunity to really further that mission and it's a pleasure to work with them.

Along with that group of individuals, John Connelly has been working with us. John O'Neill that you already met today has been working with us. And we also have a great deal of help from Jonathan Ladinsky from Mathematica who can't be here today, but who has really been the person who has provided the conceptual framework for us as we move forward, as a group of state agency folks trying to figure out how best to fulfill the requirements of WIOA.

The next couple slides will highlight some of the things we've learned from Jonathan. He's actually published a paper, I believe it's being published in the Journal of Rehab Administration. It may not be out yet, I don't know, but look for that. That will give you much more information about the conceptual background that we're using to help us work forward.

But just in these first couple of slides to highlight some of the things that he's trying to point out in terms of what we need to do to think through all the requirements of WIOA.

The first is that we want to look at the high level performance accountability that's required within WIOA. That's the strategic focus on the goals.

Now, those are mandated. That's going to happen. We're not paying that much attention to that.

Where we really want to be is at that level of performance management, where we're concerned with the activities, services, proses that are being used to deliver services. We want to know much more about those.

Our data collections in the past have not really focused in on these things very much. We've looked at individual characteristics, outcomes, but that black box in the middle really hasn't been very revealed. So that's where we can make our best contribution is trying to understand and measure those things that make a difference in outcomes.

Another way of looking at these, and this is not really new, but the outcome measures are focused on goals. We want to be concerned with process measures. That will help us become focused eventually on what are the best practices that we can use on behalf of people with disabilities. And now also the best practices that we can use with employers who will have to hire folks with disabilities.

Another way of looking at this is that what we're most concerned about is the short or intermediate term objectives rather than the long term objectives. It's those short term objectives, the data collected while consumers are still in the process, rather than those measures that are collected after they leave the system. We want to collect the data while they're still within the process.

Now, the workforce system measures under WIOA have common measures. We're all familiar with those. All the programs are within the workforce system will be using these measures. We're going to concentrate and try to come up with the measures unique to VR and which will give us the most detail about what VR can do to assist people with disabilities.

Jonathan has put together a whole list of criteria for considering, selects, and specifying performance measures. I won't go over these. I don't want to go into that detail right now but they're there for you in case you want to go into more exploration of these but also I want to refer you to the article he has written which will soon be available.

I want to focus my time now on the employer services measures because these are really brand new to the field of VR. John already mentioned the employment penetration rate and the repeat business customers. Those are basically frequency counts and calculations of percentages. Not all that difficult to conceptualize and implement.

But I want to take a little bit of time to think about the value of employer service measures. These are the measures that are going to relate most closely to achieving those employment outcomes. Now, for as long as I've been involved in VR, we've talked about employer services and we've done a lot of encouraging of VR professionals to go out there and deal with employers and open doors for people with disabilities.

Now, we've talked about these kinds of things. We've got some research projects pointing out the value of these things, we've experimented with projects and industry programs funded for quite some time. So there is some experience we can build on in terms of these employer services, but they have never been measured systematically by VR agencies. So since they're not measured, they're really not done very much and we figure if we can start measuring some of these things, they're going to be done more and that should make a difference for our outcomes.

Now, the Department of Labor has given guidance as to what kinds of services can count for employer services. And now what's clear from what they've said in their guidance is that we can't just send out brochures and pamphlets to employers and count that as a service. What we really have to do are these face-to-face encounters with employers. It has to be staff to staff. We have to provide direct assistance to employers in order to count these things. I will go over these. Some may be more possible to do than others. But it's clear their intention is that we are going to do direct service to employers. That's the big difference.

Now, there's another committee out there, the advisory committee on increasing competitive integrated employment for individuals with disabilities. It's really a great group. I don't know them very well, but they have emphasized, like has been done in the past, this demand-side perspective. They've proposed this question which is what our group is going to try to answer: What do employers need to help them be successful in hiring, onboarding, and retaining workers with disabilities? We're going to try to develop what can become performance measures for hiring, onboarding, and retaining worker was disabilities.

They've also given us some examples of what employers need. I won't go into detail here. You can follow up on these later. Some of these slides do that.

These examples clearly highlight that what's of concern here is this direct personalized assistance that will be given directly to employer staff in terms of their hiring needs for hiring persons with disabilities.

What they really do is emphasize the value of creating business partnerships. Without these business partnerships, these personalized face-to-face assistance, it won't be able to be done. So going back to those original models that we've had really I think will give us a way of doing this.

As I said, we are not without resources. For many years we have developed marketing models for VR. We've developed demand-side services models, dual customer models. These are all out there. We have experience we can build on. Right now CSAVR is working with these RSA business roundtables, setting up also business partnerships. We even have some research available that will actually provide tools to rehab professionals to assess what the needs of particular employers might be. Just as we assess the needs of people with disabilities for services, we can assess the needs of employers for the kinds of services that they're looking for.

So that really highlights the kinds of things that we hope our group can be doing over the next couple of months.

I don't know if some of you are aware of the conference that this VR program evaluation network sponsors, but it occurs every year in September. This year we're going to be in Omaha, and I think the group will be working on developing more of this for a presentation at that time and we certainly would welcome any of you to participate with that and help us with our thinking.

With that, thank you very much.

[Applause]

MICHAEL GAMEL-McCORMICK: Thanks, David.

David's remarks actually I think illustrate both the depth of data that's being collected from this transition from WIA to WIOA.

The other thing that I want to call out is that it's looking at a systems perspective too. It's not only the participant in the program; it's also all of the pieces that participant interacts with, especially the employers and the businesses that we're talking about there.

So I hope to think of it as a maturing process as we're looking at data collection here.

The next two folks who will talk with us, Lewis and Susan, will talk about the data that gets collected and how it gets implemented and used, and used for advocacy at a local level.

Lewis, come on up. We're looking forward to hearing from you.

LEWIS KRAUS: I see, Andrew, you're not going to help me on this one.

All righty. Well, I want to start by first saying thank you and acknowledging that this work was done under finding by NIDILRR and the StatsRRTC and also to say that the title is a little bit not quite correct. It's really local disability statistics and it's not just in California.

So with that in mind --

[Laughter]

Well, it's all right. It's my title. I can make a mistake.

So let me take you back to 1988 for a moment. NIDRR's first attempt at making disability statistics available publicly to people.

A young, just out of graduate school, guy is sitting there at a phone and answering phone calls about disability statistics from anyone in the country. And for a long time it was pretty easy to answer because we had national statistics and that's pretty much all we really cared about and needed.

And then somebody called me one day and said, "So can you tell me how many people with disabilities died in fires in San Francisco in the last year?"

[Laughter]

And I kind of had that laugh but I tried not to laugh on the phone because you would say, first, who collects this? Where would you ever find this? And you know, I sort of filed it away like oh, boy, what an interesting question that might be.

But now fast forward to today and really I think the point about that that I really cared to bring up with you is that national statistics have their importance. But there are agencies, there are advocates, there are individuals who have an interest in the disability data at the local level. And they want to be able to plan programs, they want to be able to generally make the case for disability needs in their particular area.

So in this project, what we did was we created a website generator that hosted and created local disability data and maps, which you could also use on a mobile phone.

And we used the ACS API to generate the date for us. And we shared it with interested parties locally and around the different parts of the country and had some discussions with them about their specific data needs.

It resulted in many efforts, not just four, but I do want to talk about four case studies here just to get a sense of for us as we're sitting here of what kind of elements might be important in the use of disability statistics where -- now, I've been to many conferences; you have too. And this phrase has not been uttered once yet today. I'll be the first -- where the rubber meets the road. Right?

[Laughter]

Okay. So we're going to look at Marin County, California disability access program, Alameda county public health, Jefferson County Alabama, and FEMA's office of disability coordination.

So Marin County is an affluent area located north of San Francisco and it's relatively known for its affluence but has significant pockets of lower income areas. The disability population in the county is 8.8%, which is below the national average.

In 2015 the members of their disability access program who were aware of our local data capability requests zip code level disability data for their county. They requested data and we discussed it and decided that zip code might be a good use for them.

Their purpose was to use the zip code data to help set priorities in programs for people with disabilities. So first, prioritizing within the million dollar a year budget they had for capital improvements and engineering by noting the existence and size of disability population and bringing awareness to their needs.

The second issue was sharing the data in order to target outreach to people with disabilities for county jobs as part of a larger diversity and employment initiative.

A third effort was to use the data to raise awareness about disability rights to county aides and supervisors. In general, those elected officials historically had not created public legislation with an eye towards the needs of people with disabilities. This was hoped to raise awareness for people with disabilities.

I know you can't read this. But I wanted to just show this to you. This is the spreadsheet that they got. Down the left side are all the different zip codes and cities within Marin County, and all the data to the right is what they received.

First a little background. You know what a zip code is. When you get to the data, you don't quite get a zip code but a zip code tabulation area, ZCTA. It's a geographic area that approximates the delivery area for a five-digit zip code.

What they received here by these ZCTAs -- that's really hard to say -- the estimated total population, the disability population, the percent of population with a disability, the number and percent for each of the six disability categories, and then they also received an error and explanation of the meaning of the error and the caution that they should have in using the data with such a small population size.

With that data, that disability access office had been able to prioritize facility and pedestrian right of way work, getting about 250,000 for fixing sidewalks and other public accessibility issues, and they described this as a success in achieving a priority where they had not had one previously.

As far as the diversity in employment, while nothing has yet occurred in their HR department with these data, they thought the increased awareness affected internal processes and now the county's HR department has included a question about disability there by allowing the county to enumerate the number of employees with a disability.

And the third area with the supervisor aides, they described this as ongoing and the respondents had a hope for a long term impact through general education of the leadership.

The quote that came from the head of the agency is, and this was really a measure of the success, it says I have the spreadsheet taped right above my computer and it's the first thing I see every day. And he goes to say, he then says, okay, what can I use it for today.

So it really has been a success for him, and I think we want to look at what did we learn about what made it a success. And the attributes I think as we note there, there was an internal advocate who had a plan for the use of the data and knew how to proceed can the data once he had it in hand. The initial introduction to the data from our team opened their eyes to the potential impact of the data in their program and policy development in their country.

Second case study here is Alameda County and their Department of Public Health. This is east of San Francisco, also the location of Oakland and Berkeley. This area has a few low income areas, and I am focusing a little bit when I talk about low income, because we've already heard about the connection between disability and poverty and whatnot so I do want to make sure this gets pointed out.

The area is racially diverse. It's also home to UC Berkeley as well as Oakland, and it's also where a whole series of new high tech workers who are unable to afford housing elsewhere in the Bay Area come and live.

The county disability population rate is 9.5%, which is still lower than the U.S. population.

In 2014 the county's public health department was undergoing their accreditation. As part of their materials they developed a report entitled the Alameda County health data profile community health status assessment for public health accreditation. And this was going to guide their community health improvement plan and they were going to -- they looked at their different populations in terms of health equity but not by disability.

We had an internal staff person who was involved in disability policy there and she noted the report contained no disability data but segmented the population in other ways, race, ethnicity, changing demographics, etc., and so since the report was supposed to cover health equity, she approached the agency director to point out this lack of disability data in the report.

She said, you know, if this community health improvement plan is supposed to guide our actions going forward, if we don't have disability data, we're going to be lost here, the disability population will be lost.

So the director agreed and asked the staff to address the concerns.

They brought in an intern to help get the disability data together, and then they also approached us. The intern was to produce a report with the voice of not only the disability community but the senior community as well, and we had a discussion with them about what was the goal of the report and how could they get to it. At first it was not intended to be a part of the community health assessment but it started internal conversations about the need, use, and appropriateness of that data and its inclusion in the report and beyond.

So the intern met with the epidemiology group and received some direction, then she met with us for more direction about what data was possible and how they could find it, and she ultimately created the Alameda County disability and older adult brief.

After its completion, we joined with the internal disability staff person in a meeting with the director to review the report, and he saw that the input of the report, and he kind of asked for direction. What should we do with this?

So we took advantage of that moment and pushed for the idea of inclusion of disability data to inform any health program planning, and he agreed.

We moved toward working with the epidemiology group there and informed them of the potential use of the disability and basically provided them with their disability awareness, which seems to be like the first step, as we're probably all familiar, with whenever you want to get somewhere in getting someone to do something on disabilities, you need disability awareness.

So the epi group looked at the data themselves. They went and did their own report and presented it to internal managers. Looked. The same as the interns but higher quality. And the interest and understanding once they made the presentation internally was immediate and the county is now embarking on trainings to staff to include people with disabilities and their needs in all their program plans.

[Applause]

Yeah. It's pretty dramatic.

So what did we learn about this success? I would say right now it's a little bit too new to say. The training agreements are still being written up and we're going to help them with their training agreements as well.

There is an internal disability awareness that has been raised within this agency. And you know, if you listen to the last one and to this one, you needed an internal advocate, you needed an external data expert, you needed open minded leadership, and then you need to let those internal mechanisms work. So once it was the internal agency said this is valid, this is it, we're going to do it. They went with it.

Okay. Next one. This is Jefferson County Alabama.

MICHAEL GAMEL-McCORMICK: I know you have two more. We're running against time.

LEWIS KRAUS: Jefferson County is the most populous city in the state. They also have a community health plan for their county and external advocates from the health action partnership, which was about 80-100 organizations that coordinated on grants that wanted this to be part of their health grant writing. They approached us for help with their data.

We created, after we discussed with them, a disability statistics for Alabama in the counties of Blount, Jefferson, Saint Claire, Shelby, and Walker. It looks just like the report you'll see tomorrow. Here's a page of what it looks like. It covered the ACS numbers and percentage of people with disabilities in five Alabama counties. And the prevalence of types of disabilities, the employment, earnings, poverty, and health, especially smoking, obesity, high BP, and so on.

And the value within the state depending on county.

The map was supported by data in tables providing the U.S. value, the Alabama value, and then the county value. And the rank within each county within Alabama. So if you look at that, for example, that Jefferson County, where they are first in the number of people with disability out of 67 counties but 46th in terms of the percentage of disability within counties in Alabama.

The report was used to inform the partners about the transportation and the size of current population and to seek further grants. They used it for the rapid health impact assessment grant around a couple of healthcare facilities for those with mobility challenges and they also provided date to the Jefferson County health department as they wrote grants and to the Lakeshore Foundation as they wrote grants on their projects.

I would just say really quickly that the awareness has been raised dramatically. The health action partnership was engaged in advocacy on the Healthy People 2020 information and particularly health equity for those county areas, and this provided an inclusion manual, shared data, and provided some trainings.

Here's some quotes from what they thought was the value of it. And it was a success as well.

"Data is part of the process to moving the needle for inclusion. Takes more than just meetings. So often statistics don't complete the narrative of the story. Data makes it more impactful."

"Really believe they would not have been as open to this capacity building."

Again, if you look back at this, it looks to me that they developed some internal advocates through previous work, they worked with external data and experts and gave the information to the organizations to work within their structure to get the results done.

And just quickly, I'm going to stop, but here's the -- just wanted to show you briefly something we did for FEMA. That screen right there is a way for FEMA to look at data, select data, for themselves in a local area by topic, by age, by gender, by state, by data set. Like that. And then they get a result right there and they can do what they were doing on their handheld phone to help them with emergency preparedness exercises.

And it wasn't as successful because they didn't have an internal expert and they didn't have an internal -- they didn't work with us really. That wasn't the reason, but you know, they didn't have an internal expertise and nobody really bought it and carried it along. So it's kind of just languished with them now.

So there we go. I think that's going to be fast enough because I want Susan to get up here too.

[Applause]

MICHAEL GAMEL-McCORMICK: Lewis, thanks for that.

Just as a reminder, the slides are on your thumb drive. You can access what he was referring to.

Susan, you will take us through some additional local use of data as well, right?

SUSAN DOOHA: Yes, I am. All I have to do is pull this up.

Good afternoon, everyone. It is a special treat for me to be here today, one day before Valentine's Day, because my presentation is a love letter to people who love data.

[Laughter]

And who may not understand that they are change agents, but you all are. And it's especially a love letter for the people at UNH and at Kessler, who have worked with me and made the last five years of my work life so spectacular. And made me agency so successful in all of the advocacy campaigns that we do.

I'm going to begin by telling you about our organization. We're an independent living center. There are organizations like us in virtually every community across the nation. We are led by people with disabilities, we are staffed by people with disabilities. I'm the executive director; I have two disabilities. And we serve people with disabilities. In our case throughout New York City.

The people that we serve are of all ages but with a heavy concentration in the 25-59-year-old range. Every kind of disability. A lot of the people that we work with, almost a majority, not quite, have multiple disabilities.

We are of all races and ethnicities. We speak all languages. We have all immigration statuses. We are of all genders.

In 2016 we reached nearly 23,000 people with disabilities across New York City. Virtually everyone that we reached, the overwhelming majority are people living in poverty on a long term basis.

What do we do? We help people make roadmaps to reach their individual goals. We screen people for benefits. We help people navigate systems and do problem solving, including administrative law proceedings. We engage people in learning about their rights. We help people become more effective advocates. And we help people learn through their engagement with peers.

We work with government agencies, corporations, and social service agencies on their legal compliance with a particular focus on the Americans with Disabilities Act, the Fair Housing Act, and disability literacy, how to improve their skills in working with people with disabilities.

We educate the public through the mainstream media and through social media, and we advocate for systemic change for people with disabilities.

Why do we use research? We think that people with disabilities speaking about their own, our own experiences is a very powerful tool, and we believe in using case studies to help educate, but we also recognize that lawmakers need to know the magnitude of an issue and who is affected.

Lawmakers always tell me, "Give me numbers." Full disclosure, I grew up in politics, I was raised by an elected official, so I learned at a very early age that numbers matter. How many people are currently affected by a problem, how many people will be reached by an intervention, what kinds of interventions are going to be more or less effective.

We also like to persuade the media that we as people with disabilities have expertise not only about our individual situations but about the experiences of people with disabilities more broadly. To boost our credibility and to share with them that we are speaking about a widespread problem. Too often people with disabilities are invisible in the media and are not seen as credible in speaking about our own experiences.

And as people with disabilities, we learn as much from research because it helps us understand how our experiences relate to the experiences of others like us. We feel less alone.

What kind of research do we use? We do phone surveys, internet surveys, interviewing, social media campaigns with this material. We create focus groups. We have discussions with key informants. We conduct on the street surveys. We use Department of Justice tools to survey our streets, our emergency shelters, our homeless shelters, you know, our transportation systems, you name it. And we come

up with findings related to that research. We've done restaurants, polling sites on Election Day, subway stations as a few examples.

We scan the literature for research. Your work. We look for your work to inform what we do and to educate us about the lives of people with disabilities and match it up to the lives that we see and we experience every day.

We employ policy experts to help us look at what's happening in other states, collect data, prepare reports, do surveys of what's happening across the country.

And most important for me in our last five years has been the partnership that we've had with the institute on disabilities at UNH and at Kessler Institute. I really have loved every moment of this experience., it's been quite an education for me as an advocate.

They provide us with statistical documentation that illuminates issues that people with disabilities are reporting.

How do we work with researchers? We have prepared 24 reports. We ask for them to answer questions using every possible database that they can think of and we can think of. We ask for data on specific topics that we're working on. Poverty, food access, health access, health coverage, transportation, families, housing, you name it. And we discuss the implications of this data for policymakers with them, with the researchers, so that they can help us tease out the implications of the data.

And we make recommendations for policy change based on our own experiences and the available data. The reports that we've done are on our website, which is at the end of our report and you'll have it in your materials, and we have published three major reports, one about the ADA at 26 in New York City, many bridges to cross in 2015, the ADA at 25, a portrait of New York City, and a portrait of every county in the state of New York.

We distribute all of these reports and using data to everyone we can. We are appointed to many public bodies and to nonprofit advisory councils. For the New York City and New York State departments of health, for the rehabilitation counselor program advisory body, for the department of finance, housing, subsidy program, for the New York City human resource administration disability advisory work group, the food stamp work group, the Medicaid redesign team the governor set up, the rehabilitation counsel, the Department of Education.

We distribute reports to the governor's staff, to our legislature, we testify at public hearings, and we always include this data in all of our testimony. And our memos of support and opposition, we include data that relates to the issues we're discussing. We quote data in every meeting, every letter, every memo, all of our reports, all of our testimony.

And we get results. We are very proud. We get results in terms of the minimum wage increase, paid sick leave, increased ADA compliance in healthcare, preserving Medicaid eligibility, access to prescription drugs and transportation, increased ADA compliance by New York City and New York State Board of Elections and Department of Motor Vehicles.

We use data collected in civil rights litigation. We are currently using data in litigation to implement the Americans with Disabilities Act in New York City and New York State. We are also monitoring the implementation of three landmark court decisions where we were the representative of the class of plaintiffs. We've cited the ACS data in our comments, testimony, proposed settlements, and implementation plans.

In 2016 we have used research data in litigation, settlement talks, and monitoring of court ordered settlement agreements. Related to New York City homeless shelter accessibility, curb cuts and sidewalk access, accessible polling sites, accessible voter registration websites, our landmark agreement on emergency preparedness and disaster response, and housing discrimination. We also are currently working on public health efforts around adult obesity among people with disabilities and access to healthy foods and communities that are impacted by poverty.

These are just a few of the things that we do.

We work a lot with mainstream and social media. If you Google us, you will see we've been in the Wall Street Journal and New York Times. We've been in the Hechinger Report. We've been on TV on CBS, on National Public Radio, on CNN, talking about the issues affecting people with disabilities and basing our discussion in the data that we have collected together with UNH and Kessler.

We have a very active social media presence, and we welcome you to "like" us on Facebook, if you did that sort of thing. We're very active in talking about issues that affect people and inviting people to have conversations about healthcare, about poverty, about employment, about housing. That we can then use to effect public policy.

We share data. We share facts. Not alternative facts. Facts.

[Laughter]

On our Facebook page.

To reach us, you can reach us by giving us a ring, by finding our website, by contacting me directly by email, and we welcome hearing from you. We know that every time we speak with you, we're going to learn something new and interesting that's going to change the work that we do and change people's lives.

Thank you so much, so very much, for the work that you do.

[Applause]

MICHAEL GAMEL-McCORMICK: I know we're running up against time but I just want to take one more opportunity to thank John and David, Lewis and Susan, for sharing your points of view and the importance of data and how it can be used at the local level and to advocate.

After listening to Susan, I'm tired.

[Laughter]

Which is a good thing because it means she's using the work that gets done here to actually make an impact on the ground. So thank you.

Give them one more round of applause.

[Applause]

So do we want to take a minute for question or do we need to go right to Michael Murray at this point?

>> Hi, my name is Nancy Crohn with the Maine developmental disabilities counsel and I really appreciate this conference. We use data all the time to be able to move our policy positions.

One of the things that we're looking at is how do we start employing systems change data to our own systems change work. So how do we -- forgive me. I'm going to read this.

We sell the data to further our cause. How do you then tease that out? Is it advocacy? Is it programs that we funded? Is that what changed the system? And how do we start evaluating our own systems change work to build stop gaps so that we can decide whether or not we are using the correct strategy to be able to actually change policy in systems change? It's challenging.

I was wondering if you have any knowledge of research to move implementation science. How do you evaluate your own implementation science using quality improvement methods?

MICHAEL GAMEL-McCORMICK: Can I just comment what a wonderful question that is?

[Laughter]

To be able to use data to look at ourselves as we move forward and try to make our systems better.

Who wants to jump in and start with that answer?

SUSAN DOOHA: That is such a fantastic question.

We think of what makes change as involving really many things. We think that it can involve grassroots campaigns, where individuals speak out. That's an important element to measure. Is the campaign that you're funding involving and engaging individuals who are speaking out about their experiences? Are they collecting their stories and using their stories effectively? Are people being trained to work as communities? Are people able to join advisory bodies that influence policy? Are people, in fact, having effect on what measures or recommendations come out of those bodies? Are we using the media to inform public opinion and to apply pressure on policymakers who are going to hear about us and what our concerns are in the media?

We believe also that litigation can be very helpful motivator for policy change.

If you think about the civil rights struggles of the '60s and the women's rights movement and the other movements that have happened, I have seen them employing all of these strategies.

I look at templates for measuring systems change that start with what we trying to affect, who is affected by it, how are they affected, and then what are all of the tools that we can employ and what are not the battle one but maybe a skirmish one in the battle and how are those stacking up.

And then I look for outcomes. Do we actually have a new law, policy, regulation, administrative directive that reflects the change that we sought? And that embodies that.

That's how we look at things.

LEWIS KRAUS: And I knew she should go first because she would have a much better answer than I would.

She told you exactly sort of the systems change kind of general methodology and whatnot. If you're trying to think about it in terms of, you know, what is the data, what does it do, how does it help. That's kind of where I was trying to make the case that I think we're getting some -- or at least I'm seeing the point of when you're sitting there deciding what is the topic that I'm trying to work on, sort of like Susan did with UNH and what the people did with us, is, you know, work with an expert in that data to try to figure out what can prove that point that you need to make.

>> Well, a quick follow up, that's what we do. But how do you -- and it works to a degree. But I'm looking for efficiencies within the systems change process. What you just listed are wonderful tools in the toolbox and those are the ones you employ.

However, on a long term, we want to make the world much more inclusive, so we're going to apply these strategies and we're going to apply these data elements at different times, but I also want to measure what we are literally doing to be able to do stop gaps and say, okay, we're moving this policy here, this is where we're being effective, how do we know that -- it's more internal. It's more how do you do it within your own systems of system change. How do you employ this work looking inward. You might not have an answer.

SUSAN DOOHA: There are other organizations looking at the same time. I think community catalyst, for example, when they grant funds look very much at what is effective.

>> Great. Thank you.

SUSAN DOOHA: And what were the barriers and the facilitators of change.

LEWIS KRAUS:

You may want to look at some of these foundations that fund as well. They might have rich ideas of how they measure it as well, something like, you know, doesn't even have to be in your field. Could be, you know, the Robert Wood Johnson Foundation or something.

>> Thank you.

MICHAEL GAMEL-McCORMICK: Is there another question for the panel.

Up front. Yes?

DAVID WITTENBURG: So my question is for you, John. You actually opened with a joke that said we're going to ignore evidence-based practices and we all laughed and whatnot. But then you went into a story of adding 100 administrative measures to a system that is untested. And this has to be done by July. And is there any way to start pilot testing? Because if you just go to -- it just strikes me that this new system is headed for disaster, at least the way it's been described. And I sort of contrast what you described with what Lewis described of what was successful in Alabama with capacity building, and I'm hearing very different things and it really brings me back to the point of the importance of piloting.

So I guess my question to you is, is there anything that we can do before July to help improve this system or are we just headed for bad things or am I just too pessimistic?

JOHN CONNELLY: No, I don't think we're headed for bad things, and I think ultimately, as my copresenters have said, there will be much good come from this as was intended by Congress.

And thank you, Michael.

But you know, or and, not but. And I think it's important to recognize, though, the challenges on the table. So as we look at what can we expect, what demands should or shouldn't we put on this system right now, and, you know, how can we help the core programs to achieve this. I think those are some of the questions.

And it goes back to your question about systems change. You know, how do you take a program and a staff and say, okay, in two years you're going to have 100 new data points that you have to collect. You still have to serve your customers that come through the door every day. Business has been your customer for a while. And now you're going to get measured on how effectively you've been serving them which you haven't been measured on before.

So to all of you in the research world and since I came with CSAVR in 2009, I've learned more from you and gotten more and more respect. The work that you do, as Susan said, is very, very important.

And I would ask you to think of David's question all the time: Well, how is my research ultimately going to help the vocational rehabilitation program? Or any of the other core programs in terms of meeting the expectations under WIOA and more importantly better serving their customers, getting better outcomes for their customers?

And there are probably a lot of answers that you can give to that question, depending on what the nature of your research is. Should I ask, for example, I got a request the other day, somebody wanted to survey 600 counselors about an issue that's not directly related to WIOA. I'm not saying that research isn't valuable, but is this the time to do that type of research and expect that type of response from the system? Probably not.

So I think it's taking into account those kinds of considerations. So I thank you as you do that.

MICHAEL GAMEL-McCORMICK: Great. Thank the panel for us one more time, and we'll turn things over to Michael Murray.

[Applause]

MICHAEL MURRAY: You guys can just stay there because I'm going to be super quick. Give me like three minutes.

Hi, everybody! Is everybody still awake? Yeah. Yeah. All right.

My name is Michael Murray, chief operating officer for the American Association of People with Disabilities, AAPD. Everybody say AAPD!

Oh, see, I really like that. One person is with me.

Okay. Thank you to our benevolent funders, NIDILRR, has anyone thanked them today? I don't know. And Kessler.

[Applause]

Yeah, no, go ahead. You can clap. That's right. That's right!

And so I mean today has been incredible I think. We've had some brilliant and amazing people up here, down there, asking questions all around. You know, I was listening to someone and they said, lagged spatial regression models. How many of you understood what that is?

I thought, ooh, look at the pretty pictures. Right? Because they were so pretty. I'm the guy where like I've got the thing and I'm like, yes, the employment of people with disabilities is improving! Then Andrew says the chart is upside down and I'm like, oh, okay.

But I love data, right? Can I join you guys as data geeks even though I don't understand everything? Right, my friend Laurie, she's also my neighbor. I was like, what is that again? What is that again? But I love data and I think it goes back to what Susan said. As we with people with disabilities at all points of the circle, whether you're doing policy, advocacy, wherever you're engaging, the work that you guys do on the research side and the data side really does influence all of it.

And so who is proud to be a data geek?

>> Woo.

MICHAEL MURRAY: Oh, come on! Who is proud to be a data geek?

[Applause]

That's why we're here! Because what do we want? Disability data! What do we want?

>> Disability data!

MICHAEL MURRAY: What do we want?

>> Disability data.

MICHAEL MURRAY: When do we want it? After peer review.

[Laughter]

But then also I think one more valid question is why do we want it. Right? Somebody said amen. I am evangelical, but anyways, that's another story.

But what do we want? Disability data. When do we want it? After peer review. But then why do we want it, right? We want it because, like, Susan was saying, Lewis was saying, it has these impacts on people's lives.

So when I look at 44% of those in rental assistance programs are people with disabilities, what do I want? I want that piece of data, right? After peer review. And then I'm going to utilize that to be able to push and improve the system, right? That's really exciting to me.

Another great example, well, let me ask you guys. I'm going to get maybe 2-3 folks. What did you get today? What did you want today? Somebody tell me. I'll bring you the mic. No, that's all right. I'll run it to them. You don't have to.

Yes. Yes, sir. Yes, ma'am. Who was that that raised their hand? I saw it back there. Was it you? Oh, you guys raised your hands, didn't you?

What do you want? Oh, she just moved?

[Laughter]

I am going to call somebody out if they don't actually do it.

What did you guys get today? What was that one thing that you went, yes!

Oh, you've got it? Go ahead what do you want?

>> Well, as a data collector geek, I guess you could say, what I got out of it was hearing people talk about ways to collect data from people with disabilities and possibly, you know, downsides, upsides, I like to see people comparing that, I like to hear about cheaper, faster ways of collecting data. So that's from a data collector geek's perspective.

MICHAEL MURRAY: And why do you want it?

>> For the same reasons that you do. I want to see it make an impact and, you know, get out there and do something better for people's lives. Same reasons.

MICHAEL MURRAY: That's right. That's right. Give her a round of applause.

[Applause]

Okay. I'm going to pick on somebody on this side of the room. What do you want? Oh, Dolly doesn't want me to give her the mic. I will pick on you if you don't say something.

Oh, you guys got it. There we go. There we go.

>> Hello. As someone who is every day very in the trenches of moving a system into great change, I know that I need data to succeed and to get to the other side of the bridge we're crossing.

But I also don't just need data; I need good data. And I need to know how it's being collected so that I can make that judgment call of this if this data is really going to sustain us as we're making those great changes.

>> Woo woo.

>> As the CEO of a provider group, you know, I have to make sure that all of the people make it over that bridge. So you know, it's the individuals we serve, it's the people who have worked in the field for the last 30 years as it was in one model and now is in a new model. So it's data that will get us there, and I've got to say that my whole organization has become data nerds. I'm really glad about that.

[Applause]

But so that's what I got out of today.

MICHAEL MURRAY: Give her a round of applause.

[Applause]

So what do we want?

>> Data!

MICHAEL MURRAY: Disability data. That's the answer. When do we want it?

>> Now.

MICHAEL MURRAY: Now. We want it after peer review. And I think that's the point that she was trying to make too is that we get faced with a lot of data a lot of times and our gut will tell us it's not right but without the brilliant folks here doing this kind of research and then trying to explain it to those of us who are less data geeks but still love the data, we wouldn't have anything to go back to folks on.

Great example, I worked at the U.S. office of personnel management implementing executive order 13508 on increasing federal employment of individuals with disabilities in the federal government. We had a goal of increasing employment by 100,000 people.

But utilizing data on a regular basis, getting people to utilize that date in their agencies on a weekly basis, reporting to their leadership on this data where are we going, where are we at, utilizing that data like the retention data, we pulled some interesting stuff. The number one reason that federal employees leave federal service. Anybody got an idea?

>> Retirement.

MICHAEL MURRAY: Right. It's above 50%, right? The older you get, the more likely you are to acquire a disability. The more hair I lose, the more my knees hurt. The guys in the crowd get me.

So we saw that. But then we also saw that some employers are like, well, we hire people with disabilities but then they leave and they resign at really high rates.

But actually, the resignation rate in the federal government, we're talking about a data set of 2.5 million people, the resignation rate was 2-3 percentage points lower than people without disabilities. So we were resigning at lower rates than other folks.

But without that data, I couldn't go to an employer and say, "This is a good deal." Ultimately that affected 501 of the Rehab Act that just got fully announced and will start to be implemented which is a big deal, right? And we were able to set percentage goals for every one of the agencies for GS-10 and below and GS-15 and above and really move things forward. Section 503, the rules we have there for 7% utilization goal all because we have data to back it up.

So again, I think what you guys do on a regular basis is amazing. It really helps us make all of this happen, and you guys make this happen and informs us every step of the way.

I think just leaving today realizing that, you know, when you're looking at the SIPP or the, what is it, the American Community Survey or whatever and you're stuck behind your desk for hours and hours on end, realizing that this stuff has a very substantial impact on a person with a disabilities life and that each number has a name and each name has a story and every one of those stories in some way through this work that you're engaging in, you get to impact.

And man, that's powerful.

So thank you guys for being here. Thank you for being a part of this. Thank you for the research that you do. And we'll keep moving forward.

I'll see you guys tomorrow morning. Do we have any announcements before we go?

ANDREW HOUTENVILLE: Just be here.

MICHAEL MURRAY:

At -- Penny? She's our brains and the brawn. 9:00? 8:30 registration, 9:00 Andrew Houtenville.

Thanks, everybody.

[Applause]

[Conference ended at 4:17 p.m.]