>> ANDREW HOUTENVILLE: Hello, everybody. We'll get started in a minute. I'll just give a few more minutes. We're up to around 225 or so participants right now. I'm going to flip to the logistics page just as some up-front logistical information, some Zoom tips about making sure you have the right sound and audio settings. And also, making you aware of the closed captioning option, which is available to show subtitles, as well. We have around 1,000 people that registered, over 1,000 people registered. We're at 250 or so participants right now. We'll have to figure out what's the best. 268. Let me go ahead and get started so that those of you who came on time have the benefit of the full webcast. Just a few up front matters, as well, we are spotlighting the ASL interpreters today for accessibility best practices. For folks on a computer who like to have multiple speakers alongside the presentation, go to "view options" and you can see "side by side" mode under view options. And you can also select the gallery view. Zoom is changing a lot of things over time. Some are easier and some are less easy to adapt to. This website is where you can also find the compendium report, and state-level reports that we will be talking about. If you did not request a copy by mail, they're supposedly going live this morning. I'm hoping that happened. I was teaching this morning, so, I didn't have a chance to see whether the website was updated. I'm waiting for a text to say, "Yes, of course it was."

>> KATE FILANOSKI: It was.

>> ANDREW HOUTENVILLE: Through the speaker from on high. This website is where you can find the slides as well as speaker bios. As an attendee of this webinar, you are a viewer. To ask questions, go to the Q&A box on your webinar screen and type your questions into the box. Speakers will have the potential of seeing it. They may potentially answer on the fly. But we will have a Q&A session where we will be the moderators and I will help review the questions and speak to them, as well. If you have any questions, you can e-mail us at disability.statistics.edu. Or the toll free number if you're interested in more information. I'm going to turn it over to the moderator, which is me. I'm going to go back up to the front slide. Welcome, everybody, to the Annual Disability Statistics Compendium. We're going to start calling it the Annual Disability Statistics Conference. This was initially a morning session on Capitol Hill where we would release the compendium. We've since expanded our products to include the annual report, the supplement, infographics, all of which we'll talk about today. But we've also expanded it to be a full-day conference. Of course, in Zoom times, we can't have the four sessions in person. We've decided to break it up into four bits for an hour and 15 minute sessions instead of having one session all day and having lunch which we've been doing for the last 20 years in various forms and shapes. We're going to break it up and do Zoom days: four days like this one. We're going to have four days all at noontime. We're going to talk about the annual report. We're going to do the statistics today, all the products. Day two, tomorrow, at noon, will be our federal partners, federal data collection agencies. We'll talk about the latest things that are going on, particularly related to COVID. On day three, we'll have the impact of COVID and we'll have a set of speakers talking about COVID-related data that are coming out that are starting to come out. And understanding the impact of COVID-19 pandemic on people with disabilities. And then on day four, we'll have speakers speaking to disability and the African American population. We'll hear from folks from Langston University, as well as present the results of an infographic that we will be publishing every year going forward. With that, just before I before I turn it over to Phil Beatty from NIDLER for just a few words from him, let me tell you a bit about what we're hoping to accomplish. From my viewpoint, statistics are a really powerful tool. A tool in science and research and advocacy and policymaking. They're also an important source of identity. When we first started compiling statistics related to disability back when I was at Cornell, there was really only, there was no annual source of statistics. There was something called the annual statistical abstract of the United States. And the statistical abstract was this big book that sat behind reference librarians. It was discontinued. It was put out by the Department of Commerce of the United States. It had over 1,000 tables and not once did the word "disability" or "disabled" or "handicapped" This was a long time ago, so there were older terms - None of those terms showed up. There were no tables dedicated to people disabilities and the federal and state programs related to disability. Out of 1,000 tables, there was not one. That led us to build a statistical abstract like the compendium. There's all kinds of data that we put in. Population data, Program-based statistics. Increasingly statistics are being used in business analytics. I'm sitting in the middle of a business school and business analytics is going gangbusters in terms of the use of data. And if we don't have measures of disability in the data sources that are being measured or being collected, then, you know, it's really hard to promote the lives of people with disabilities to do research, to do policymaking advocacy if we don't have the measures of disability identifying the population alone, let alone aspects that are specific to people with disabilities. So, we'll be talking a lot about the data sources throughout the conference and, you know, really trying to come together as a community to advance the world of disability statistics. Of course, we couldn't do this without our funding from the National Institute on Independent Living ...NIDILRR. We're going to hear now from Phil Beatty for a few minutes. Take it away, Phil. Hello?

>> PHIL: Thank you, Andrew. I was just able to unmute myself and, I believe, to start my video. Yes, thank you, Andrew. And hello, everyone. Good morning to those of you in the time zones to the west, and good afternoon to those of you in the Eastern Time Zone. As it has been for the last couple of years, it's my real pleasure to welcome everyone to this important event. Welcome on behalf of all of my colleagues at the Administration for Community Living and the National Institute on Disability Independent Living and Rehabilitation Research, or NIDILRR. I want to start my words of welcome by thanking the center on disability statistics demographics and graphics. Each year the disability statistics RRTC systematically pulls together data from every available source to produce this strong core of national, state, and county-level disability information. As a result of that solid and systematic work each year, the compendium is a central source of really good data about and for people with disabilities across the country. The compendium really is centralized informational infrastructure, as Andrew said, for people with disabilities, for disability advocates, service providers, policymakers, researchers, and all kinds of other stakeholders across the country. So, at the same time, the rollout of the disability statistics compendium each year is a real opportunity to discuss and prioritize pressing topics related to disability measurement, analysis, and reporting. To make this point really clearly, let's just reflect back to last year's compendium rollout. Exactly one year ago, many of us, many of us were gathered for this event in a large meeting room in a hotel near the capitol. Many of us had flown in for the event from places all around the country. We were sitting shoulder to shoulder. We were giving each other welcoming hugs and handshakes. We really had little idea of the coming national public health emergency and pandemic that we'd all soon enter, and the implications of the pandemic for our lives and for our shared work. Also, a year ago, we didn't know the names Breonna Taylor and George Floyd. Their killing among so many others that came before served as catalysts for nationwide and international demands for racial justice and racial equity. These have quickly and importantly become the defining events and experiences of our time. And within the context of these public health and social justice imperatives, the RRTC has put together an excellent program of presentations and discussions. They've invited experts from across the field to present and discuss disability measurement and statistics work that pushes our shared agenda forward. As Andrew just described, many of the presentations will focus on COVID's impact on people with disabilities. Others will focus on social inequities among people with disabilities by race. And many of the presentations will combine both of these topics in important ways. So, really thank you to everyone on the RRTC team for pulling together this key data information as you do each year and really thank you for rolling it out to us through a thoughtful set of panels and presentations and discussions. With that, I would like to thank our researchers for being part of this program. On the program this week, I am looking forward to hearing from experts from the Census Bureau, the CDC's National Center for Health Statistics, as well as the Bureau of Labor Statistics and the Office of Disability Employment Policy, within the Department of Labor. We'll also hear a presentation from an HHS colleague from the Office of the Assistant Secretary for Planning and Evaluation. And of course, we welcome and we recognize all of the excellent statistical and analytical expertise from the University of New Hampshire and Langston University and Mathematica. We want you to continue this data rollout as part of an ongoing discussion with us, toward high-quality data, and analytical information that we can all use to promote an advanced, strong, positive, health employment and community living outcomes among people with disabilities. To the extent that the technology allows us, please engage with the presenters during the panels today and in the weeks and months to come. With, that I'm going to turn it back to you Andrew and the RRTC team to get us started on the data presentations. So, really thanks again for all of the excellent work that you're doing and for the excellent program that's to come now and for the rest of this week.

>> ANDREW HOUTENVILLE: Okay, great. Thank you, Phil. I appreciate it. Phil is the research director at the institute. Phil and I were flying on a plane about 20 years ago going to a site visit when I first met Phil. It's great to hear from you Phil. And thanks to everybody at NIDILRR. A lot of them will be the moderators moving forward. You'll see them sprinkled throughout the next four days. I am the moderator of the first session. You're gonna see me quite a bit today. Today we're going to hear from folks around the annual report, which I'll do, the compendium, which Shreya will do, which Shreya will do. Marissa and Megan will talk about our state reports and infographics. And then we'll hear from Stacy about a compilation of methods that relate to data collection that Mathematica has produced for the center. I'm going to share my screen. We're a little bit behind. Alright, so the annual report. The compendium we've been doing for a long time. But in recent years, we've added the annual report. And the annual report is really in the most recent years has taken on the focus of looking at time trends over time. So, this is work with me and Marisa Rafal. Marisa. Okay, let's get the page down to go. There we go. So, the goals of the annual report are to ensure a presence for people with disabilities in the context of social and economic progress. We're going to be tracking year-to-year key indicators relating to the size of the population with disabilities, the economic wellbeing, and overall wellbeing of people with disabilities, and the contribution of the environment of the enablement/disablement process. We'll also be trying to make a call about did it go up or down from last year. Now, of course we don't have yet data for 2020 from the primary sources of data that are used in the compendium and the annual report, which is the American Community Survey. So, next year will be very, very telling because that's when we'll have the first kind of COVID impact for a lot of the indicators that we can track. On Thursday, we'll have the panel that goes over what existing data we do have on the COVID pandemic. We'll also be looking at statistical significance. In order to make the call, we have to actually look at statistical significance to see whether our sample, we're able to detect whether there's an increase or a decrease. We don't have the population statistics for the entire population of the United States, but we have a sample, a very big sample in the American community survey. Sometimes we can detect changes, sometimes we can't. Sometimes the changes are small and they're harder to detect. Note that this is not the same as meaningfulness. Meaningfulness is for you to decide, for people to decide, for expert panels to decide, what is a meaningful change. First we have to see whether it's due to a sample, it's sampling variation or not. Once statistical significance is determined, the meaningfulness of it needs to be discussed in a broader context. We'll also focus on gaps and the changing gaps between people with and without disability. We do gaps just as the straight difference between people with and without disabilities. You can do it in terms of ratios, which in some aspects is better. But from a knowledge translation perspective, people really want to know what's the change in things from one year to the next. Let's talk about a summary of the results from this year. A summary over much of 2017 to 2018, there wasn't a great deal of change between '18 and '19. Of course, we probably expect a lot of change between '19 and 2020, except for a few things. There was an increase in the size of the U.S. population with disabilities percentage wise. This is likely due to aging of the population. There is a narrowing of the employment gap. This was actually seen if you follow the nTIDE report with Kessler Foundation and AUCD that we do at UNH, that we've seen there was a narrowing of the employment gap. We see that in the current population survey. We also see it in the American Community Survey. This is when the economy was at full employment, we're chugging along and this was all pre-COVID. There was also a narrowing of the recent construction gap between people with and without disabilities. This is one thing we tried to look at the relationship of the environment and the potential for people with disabilities living in older housing. So, that gap between people with and without disabilities, people with disabilities typically live in older forms of housing. That gap has changed. And narrowed. And then we have something called the disablement index. The difficulty that they have going outside the home on errands. This is why it's called the disablement index. It's the degree to which the environment appears to be influencing the ability to go outside alone and run errands. We also, many of the gaps that we compared between, one thing to note is if you go back to 2008, the first year we have the data, many of these gaps have statistically changed. And that's something you can go to the compendium for. Here is a listing. This is a bit of a shock. But these are all the indicators we currently have. One shout out is for the National Organization on Disability. Sorry, NCD. The National Council on Disability. The National Council on Disability has a really great report that's oh, probably about 12 years old now. Yeah, 11 or 12 years. That looked at indicators. If we were tracking progress, what would we track based on available data. And many of these indicators were cited in that report by NCD as being important to track. We're looking to add more indicators and we're thinking about adding indicators. But these are the indicators that we're looking at. So, we're simply looking at the percentage of people with disabilities. Then we're looking at the gap between living in institutions. We don't have a good measure that's publicly available for the number of people living in institutions that would go to the University of Minnesota, our colleagues there for that information. We have the high school gap, the college gap, the employment gap, the earnings from work gap among full-time workers, we have the poverty gap, the health insurance gap, the private health insurance gap, the mass transit to work gap. So, that's kind of getting at people's access to public transportation whether they're living in an area that has access to public transportation. The age of housing. That recency thing that we're talking about. And then the disablement index. Way over here on the right side, you can see. Oops. You can see the ones that increased. There was an increase from 13.1 to 13.2. A decrease in the employment gap. And a decrease in the recency of when homes were built and the disablement index increased. And I think we're getting short on time, so I just want to kind of point out, you know, all these trends. We have charts in the annual report. Many of you have asked for and we've mailed you the annual report. But it's really, you know, are we making progress? I think that's really up to all of us to kind of look through the data to make that. I don't want to be the only one. I don't think it really rests in any one person or any group of people to make sense of whether we're making progress, whether the change in these indicators indicate progress. I will say I'm just going to point to one thing as an economist that I would look to. And that is we saw a decrease in the employment gap over the last few years when the economy was doing well and we were in full employment. But we're still not back to, we're just not too far away. The gap between people with and without disabilities is still pretty much where it was back in 2008 the first time. Also, over this time of increasing, I'm sorry, decreasing employment gap, we didn't see the poverty gap change. You know, this is the percentage point difference between people with and without disabilities. We really didn't see a change in the degree to which there's a differential poverty gap between people with and without disabilities. So, I think there was improvement, but I don't think it's been widespread or necessarily impacted the way people are living. With that, I'm just going to show you our quick contact information where you can get the annual report. Also the monthly nTIDE report, which you can get at our web page. With, that I'm going to turn it over to my colleagues. I think Shreya is next, right?

>> Shreya Paul: Yes. Thank you, Andrew.

>> ANDREW HOUTENVILLE: Take it away Shreya. Shreya is new to us this year. Welcome. She has led the effort to build the compendium. Take it away, Shreya.

>> Shreya Paul: Thanks, Andrew. Okay. So, hello, everyone. My name is Shreya Paul and I'm a project director at the Institute on Disability. And it's my absolute pleasure to welcome you to the 2020 Annual Release of the Disability Statistics Compendium. So, through this presentation today I'll be describing the need and the purpose of the compendium, introduce the compendium content and features, how to access the compendium and technical assistance if you may need it, and finally describe a few uses of the compendium. Disability statistics, as we all know, are often difficult to find in the United States. And if found, they are often scattered across multiple sources. Through the compendium and the supplement, we aim to provide a comprehensive compilation of these statistics all in one place. Our number-one goal is to bridge the gap between the producers and the consumers of disability statistics and to do so in an accessible and timely fashion. These are some of our current products. The annual disability statistics compendium and its supplement. These two products provide estimates on different indicators, such as prevalence of disability in the United States, employment, earnings, housing, and occupation, and so on. The annual report on people with disabilities in America as Andrew described it, it tracks the progress of people with disabilities using key social and economic indicators. Next we have the state report with county-level data on which my colleague Megan Henley will expand on. But these reports are available if you want to look at county-level data on prevalence, employment, and poverty. Currently we just have these three topics. And finally, we have the infographics, which are quite popular among our products. And this year we have two of those. The first one on rural people with disabilities and the second one on African American people with disabilities. So, this is how our products look. This year we have the HTML and PDF format for all of these. And our team works really, really hard to make all of these comprehensive, accessible, reliable, and timely. If you want to download our products, request copies by mail or contact us with any questions or for technical assistance, please visit www.disabilitycompendium.org. Fun fact here. Between September 2019 and September 2020, our products were downloaded as many as 8,186 times. So, that's a big number. For the compendium, supplement and annual report, we pulled our data from a number of data sources. Some of them are listed on this slide. One of our major data sources, we used the public use microdata sample files and their five-year estimates. Their five-year estimates are generally used for the state report with county-level data. And it's also used by the university of Montana who collaborate with us for the rules section of the compendium. The next data source is Behavioral Risk Factor Surveillance System or BRFSS. And we use this data source to produce estimates on risky behaviors, such as obesity, smoking, and binge drinking. We also report benefits on various income and benefits obtained by people with disabilities, and these data are obtained from Social Security Administration or SSA or Veterans Benefits Administration, VBA. Another report that we produce is on the Vocational Rehabilitation Services received by people with disabilities and that data is obtained by rehabilitation services administration, or the RSA website. The population size, prevalence, disability type. Currently we report six major disability types: Hearing, vision, ambulatory, cognitive, self-care, and independent living disability. We promote estimates by demographic characteristics, that is age, race, and sex. The other estimates include health, health insurance, risky behavior as I said before, employment, earnings, poverty, SSDI and SSI, special education services from the IDEA act and their outcomes and many more. There have been a few changes this year. For example, the previous year we calculated different estimates for different age groups. For example, for functionality, we used the age group 24-64 years. For housing, we calculated it for age group 15 + but this year for increasing the consistency of our reporting, we have based most of our calculations for the age group 18-64 years. The second change that is there in this year's products is that for reporting employment and poverty to last year, we used census bureau's one-year estimate. But we have calculated all those estimates using the PUMS data files this year, so you can expect that the estimates are based on an edited sample. Though we do not have any brand new section in the compendium this year, these are some of our newer sections, which were introduced just last year. These are functioning industry and occupation, home environment, and rural. Moving onto the next section, which is about using the compendium. As Andrew pointed out, statistics are a powerful tool. And it is often used as a decision-making tool and very often used to monitor and evaluate the effectiveness of a policy and program. Many times doing just a quick visualization can help us make inferences about the current situation. Let's see an example here. The prevalence of disability in the United States in 2019 for the age group 18-64. As we can see, Arkansas, Missouri, Kentucky, West Virginia, these states have the highest percentage of people with disabilities. Whereas the bigger states like New York, California, and Texas have one of the lowest percentage of people with disabilities. So, knowing the size, composition and geographic location of populations with disabilities, it's very important to support the allocation of public funds to public programs. And if we do such visualizations for say employment, health, poverty, we can make inferences about which states the government needs to expand opportunities. So, that was one of the examples of how we can use the data that is there in our compendium and the supplement. Moving onto the next slide. It's about our ongoing efforts. We are continuously trying to include new sections in the compendium. One of the sections that we are currently talking about is the mental health and substance use by people with disabilities, even if we can only get hold of national-level data at this moment. We also want to expand the state reports with county-level data. Currently we have just three topics: Prevalence, poverty, and employment, but we are looking to expand to more topics. Infographics, again very popular products. We want to produce more of them. And finally, make the reports and the website more user friendly and accessible going forward. So, that was it. If you have any questions, particularly for me, please reach me at Shreya.paul@UNH.edu. And if you need any technical assistance or have general questions for the team, please reach us at disability.statistics@UNH.edu. Thank you very much for joining us today. If you have any questions, I'd be happy to answer them after the session. I will now invite my colleague Megan Henley who will do a presentation on state reports with county-level data. Thank you.

>> Megan Henley: Great, thanks, Shreya. I'm just going to share some slides here. My name is Megan Henly. I'm also part of the Stats RRTC team at the University of New Hampshire. I'm going to describe a little bit about the third in the series. The state reports with county-level data. I'm going to give a brief overview to let you know what to find in these reports and I'll show a couple of graphics to show how they may be of use. Now all of these data products are here to fill a need and many have been made because of requests in the past or anticipating what will be needed based on conversations with data users. If you want to gather information about the size, but we have different products for different needs, as Shreya was describing. The first two presentations we just had the compendium and supplement. And that's showing the most recent figures for what's happening at the national level and at the state level. And earlier, Andrew highlighted the annual report. And that's great for showing trends over time at the national level. So, what's changing and what's improving. But, you know, if you are interested in local level issues. If you're doing issues specific to a state and you want to know about county-level variation or what's local to your community, then those national level numbers may not be particularly useful to you, because keeping in mind that's a midpoint. And if your particular local area isn't maybe one of the tails of that distribution, it may not give you the best picture of what's happening. That's really the goal of what the state reports are doing. These are some of the same tables that you'll find in the compendium, but they have data reproduced for every county and every state. So, the most recent reports that we have available use data from the American Community Survey five-year estimates. The 2019 data were just released late last year and so these reports were just produced in the last several weeks. There is one on employment of disability status and one by poverty for disability status. Again, these topics, they're in response to data users' needs. And we're hoping to expand upon these and provide additional reports in future years. So, if you have a particular topic, especially one that you see in the compendium, some of them we may not be able to have state-level data just based on the availability of the reporting, but many of them we can do. So, we'd love to hear what's of use to you in your local community. If it's not something we'll produce for next year, it's definitely something we can respond to and give you that data for the area of interest to you. Just be in touch with us. So, what you can expect to find in these reports, you'll find the summary tables just as you'll see in the compendium report. But we also have some heat maps, which are useful. I have a couple of examples that I just threw up here just to provide some context so you can think about how to view and interpret these. So, this first example here is showing from the disability prevalence report, this is a heat map for the state of Maryland. And it's showing the percentage of people with disabilities by county. The lightest color blues have the lowest prevalence, in this case it's under 9%. And the darkest blues have the highest percentage, and that's 15.7% or higher when you're looking at Maryland. When you see a map like this, you can quickly understand that for the most part we see low rates of disability prevalence throughout the state, but then two counties at opposite ends of he state stand out as having higher prevalence. One is in the upper northwest, Allegheny County, and along the eastern shore, Dorchester County. And then disability prevalence, instead of the percentage, we look at the count, we see quite a different picture. This is looking at the number of people instead of a percentage. You see the counties with the largest number of people with disabilities are concentrated around the District of Columbia and Baltimore areas that are more densely populated, as well. I just noted we have a live question that asks about how we can use results, particularly the state-level reports to talk to local-level legislators to provide better opportunities for people with disabilities was the question. So, I mean really, you know, this is just looking at disability prevalence. I also have data on disability employment and poverty. If you're looking to kind of think about disparities, you might want to look at the percentages. Like, and this is where you're going to be highlight and look at the differences. If you're looking at where you want to make the greatest impact where the largest number of people are, you may want to look at these counts, the heat maps with the counts and focus in on those. So, we would love to have a bigger conversation with anybody who has specific requests about how to tailor the data to address a need. Sometimes having these reports available to you are useful as starting points to see just what data is available. But if you're not sure, you know, what you need, we're always open to kind of filling that data need because our goal is to provide the information to answer those questions. So, I just wanted to provide these as kind of a brief overview of what you'd expect. We would really love your feedback if you are using these about how they've been in use. So, we'd love to be in contact with you about that. But in the meantime, I'll turn it over to my colleague, Marisa Rafal who would like to highlight a different data product.

>> MARISA RAFAL: Thank you very much. I'm Marisa and I'm excited to present the numbers for this year's rural infographic. If you could advance the slide. Thank you. Just as kind of a background, the statistics and demographics RRTC team will make a new infographic each year and will update the previous ones. This shows the updated numbers for the first one in this series, which was U.S. Rural Disability Statistics. On Friday a new one will be released, which is Disability Infographic: Social Inequities Experienced by African Americans. On the screen, this shows the updated numbers for the 2014-2018 ACS 5-year data. That's where this came from. Last year it went up to 2017. And on the left is just kind of a screen shot of the infographic, which if you requested it you might have received by mail or it might be on its way to you. Just as some definitions before we jump in, urban counties are referred to as metropolitan and those have an urban core of 50,000 or more people while rural counties are micropolitan. And noncore have no urban core with more than 10,000 people. In more rural places, disparities widen. When looking at prevalence, what we found is that disability prevalence goes up the more rural a place becomes. So, metropolitan or urban counties had a 12% disability prevalence rate, going up to 15.8% in micropolitan counties and then going up 17.9% in noncore counties or those most rural counties. Also with poverty rate, 1 in 4 p people with disabilities in the most rural places experience poverty. This is a fraction of an infographic, if you want more concrete, they're in the disability section of the compendium. And finally, with employment, we found that the employment rate for people with disabilities ages 18-64 went down as places became more rural. So, there was an employment rate for people with disabilities 18-64 of 36.8% in metropolitan counties, going down to 33.1% in micropolitan counties, and 30.7% in those noncore, most rural counties. That's a broad overview. We would like to give a huge thank you to our collaborators at the University of Montana RRTC: Rural. If you have any questions, reach out to [Disability.statistics@UNH.edu](mailto:Disability.statistics@UNH.edu). Or you can e-mail me directly or Megan. To that, I will pass the virtual mic to Stacie Feldman from Mathematica.

>> STACIE FELDMAN: Thank you. I'm just going to share my screen. Great. Well, thank you for providing me with the opportunity to present the compendium of disability data collection methods. Before I begin, I'd like to thank NIDILRR for funding this project, and I'd like to acknowledge the co-authors, Jason and William. It's critical for organizations involved in quantitative and qualitative data collection efforts to consider the extent to which their methods create barriers to participation for people with disabilities. However, there are few available resources to address this problem. To fill this knowledge gap, Mathematica created the compendium of disability data collection methods.

>> KATE FILANOSKI: Stacy, I'm going to pause you real quick. We're not seeing your screen right now.

>> STACIE FELDMAN: Oh, I'm so sorry.

>> KATE FILANOSKI: No worries.

>> STACIE FELDMAN: How about now?

>> KATE FILANOSKI: Perfect. Thank you.

>> STACIE FELDMAN: Sorry about that. Oh gosh.

>> KATE FILANOSKI: It happens.

>> STACIE FELDMAN: Sorry, one second. So, the compendium is an accessible source of information associated with collecting data from or about people with disabilities. It includes 441 indexed references published from 2012 to 2020 that summarized papers and presentations that discussed challenges and best practices for collecting data from people with disabilities. And systematic reviews of various screening and measurement tools. We view the compendium as a living document. We continue to gather references throughout the year. We publish an updated version of the document each year to coincide with the release of the annual disability statistics compendium. Here are other broad subject areas that the compendium covers. Each of these subject areas are further broken down by subtopics. For example, under Disability/impairment type, sub topics include aging and later life disabilities, developmental, intellectual, and cognitive impairments, as well as sensory, communication, physical, and psychological impairments. Data collection subtopics include adaptive technologies, proxies, inclusive strategies, and participatory action research, interviewing techniques, and qualitative methods. The special population subtopics are youth with disabilities and veterans. We recently added reference to three ongoing national surveys. American Community survey, Current Population Survey, and National Health Survey. They're ordered alphabetically and most contain a URL. We place the references in all applicable categories, therefore many of them are indexed under more than one subject. To create the compendium, we conduct a literature search each year on the topics that I just described. We obtain articles from a host of online journal sources, conference presentations, and working papers and dissertations. After completing the literature search, we apply eligibility criteria to further specify which references we should include in the compendium. We include resources that discuss, examine, or test methods used to collect data from people with disabilities. We do not include references or articles that primarily focus on analyses or findings from survey data. We consider publications and presentations from all over the world. We screen out any articles for which the full text is not available or accessible or published in a language other than English. And due to time and resource constraints, oops, sorry. Sorry, due to time and resource constraints, we do not evaluate the methodological quality of the references. We added 110 new references. We wanted to give you a flavor of some of the research questions that are addressed in the articles and references we added to this year's compendium. There's a lot of interesting material. For example, focusing on the first bullet, Elizabeth and colleagues provide recommendations about conducting in-depth interviews with people with dementia. Topics discussed include interview guide preparation, recruitment, obtaining consent and assent, conducting effective interviews, analysis and interpretation of data, and effective communication of research findings. In particular, they noted that providing strategies to support interviewees with the symptoms of data, such as repetition and rephrasing of questions, developing single-faceted questions, and the use of visual prompts are key to developing interview guides. And here are a few more research questions focusing on the first bullet, my Mathematica colleague Jesse Chandler tested the feasibility of collecting web survey data from a sample of VR applicants, inviting non-respondents to complete a telephone interview. People were provided a mobile device. Respondents who elected to complete the survey online versus by telephone differed in level of education and VR experience. These findings suggest that for disability studies, web surveys are an important supplement to, but not a replacement for traditional data collection efforts. To access the compendium, it will appear on the disability compendium website after this event and it is currently available on the Mathematica website at this link. For more information, please contact my co-author Jason Markesich or myself. And thank you to University of New Hampshire, NIDILRR ACL, and the Department of Health and Human Services. Thank you.

>> ANDREW HOUTENVILLE: Thank you, Stacie. Let's get back up and running. We've got a lot of Q&A. Thank you for being on time. I'm sad to say I haven't been listening to my colleagues, but I have been responding to things on Q&A. If you've never been to the disability statistics compendium event live, for many years we've tried to expand and have as much Q&A as possible, which is why we're going over an hour today and going onto the next 15 minutes. We've got lots of people asking questions. We will stay on afterwards to answer questions after we close down. Let me share my screen and then I'm going to start going through some of the questions. Some of the questions we've already answered. If you're interested, there's a lot of very interesting questions that have been asked and answered. Let me first share my screen so that we get the information up there. Doo, doo, doo. Oh, I did it again! When you go too far it stops sharing. I'm just going to leave it on that view. All right. So, thank you to all the presenters. You can find the compendium at disabilitycompendium.org. You can also find things on researchondisability.org and thank you to NIDILRR. Let's go ahead and start the Q&A section. I think you'll actually see a black box.

>> Kate Filanoski: I think we were going to have people turn on their cameras and stop screen share for the Q&A.

>> ANDREW HOUTENVILLE: That's good. Now you can see all of us. I'm going to go through a couple of the ones that we already asked and answered. A couple of people raised the issue around needing more specificity. So, looking at different age breakdowns, race, gender, ethnicity. Some of those you can find in the compendium supplement. The compendium supplement was designed to put out more breakdowns because people were asking for them. We also as I believe Megan mentioned, we have the ability, much of this data we have at our fingertips and can re-estimate using different age breakdowns or race, gender, where certainly if people are interested and really need a very specific kind of information, we're happy to do that. Also for the U.S. territories and the Virgin Islands, the commonwealths, the American Voice Survey has some of that. Puerto Rico is well represented in the data sources. Some of the other territories, not so much. Give us a call. We may be able to ...help you out and find what you need. The idea of onset. So, it was raised that a lot of these are working age, and we don't necessarily know whether people acquired it in later ages. Particularly with employment. The employment of people who perhaps acquired the disability during an occupational incident, right? An accident, an on-the-job accident may be very different from people who had a disability since birth and went through the education system and into the labor market already having their disability. Unfortunately, a lot of the disability data sources do not have, almost all of them are pretty limited in their ability to look at disability onset. Someone raised the issue of rare conditions. So, low-incidence disabilities, low-prevalence disabilities, rare diseases. You know, the compendium and a lot of the work we've always focused on things that are annually updated and available at state levels. And that's where low incidence, rare conditions don't fit well within our current kind of mindset. But certainly, we could add them on the national level and then update them whenever they're updated. I mean that's the issue. They are rare conditions. They many times are not asked about in the data in the surveys and information we have. So, I think that that would be something, Shreya, that we could look at next year. We did provide tables for the survey of income and program participation. But when that didn't get updated after several years, we dropped it. That was annual data that got more detailed. Not necessarily rare diseases, but more detailed functional limitations and conditions. There was a question, a good one, on the provision of standard errors, of confidence intervals, margins of error. We do impose a sample size restriction that kind of a minimum sample size. But that sometimes still isn't enough and you could get big jumps particularly for small areas like say Wyoming or Rhode Island. Small areas. You could get big jumps from year to year. That's simply due to sample variation. And from an advocacy perspective, that could lead you down a road that's not appropriate. We've had this issue years and years ago. The census had this issue not with anything that we produced, but there was an issue where the City of Chicago went from like, you know, a million people with disabilities to half that. I forget exactly the number. And people were really concerned about that. And that was an issue. So, we continue to struggle and figure out ways to disseminate confidence intervals. Now with the ability to produce things online faster, that's certainly something that we'll reconsider our strategy around that. Because, you know, our sample size restrictions deficient or not. A lot of folks have asked about data on children. So, when I used to kind of take lots of calls and requests for disability data, there were three areas. There was location, so, state-specific. People were really interested in state-specific. That's one of the reasons why the compendium is focused on states so much. There was disability specific. And then there was data on children, right? For many years, those were the big kind of requests that came in. Data on children is a really interesting one. There's several people who have asked about data on children. And I'd have to say that the compendium is definitely, and it's partly due to data availability and partly due to looking at a lot of economic indicators. But we could do child poverty. You know, how many children with disabilities live in poverty. We could add more child-based statistics. We do have the IDEA data that is available, the IDEA meaning special education data. We have some of that data in the compendium. But some of the data sources that collect information on the population with disabilities are not great at collecting information for children with disabilities. It's hard to know how families are responding to some of these questions when they're answering these questions. But again, if you're interested in more specifics, we can do technical assistance and provide some of these stats based on children. Developmental disabilities. So, this is a big issue. And I think was it last year? Or the year before? We focused our whole conference on statistics related to developmental disabilities, people with developmental disabilities. There is a big effort at the, oh, nudge, nudge, somebody just nudged me. Some questions are to other panelists. Okay, I'm going to stop talking. I'll finish my question. If one of the other panelists wants to chime in, let me know. So, get ready Shreya, Megan, Stacie, Marisa, and maybe even Phil. Let me finish up that one question. A developmental disability. At the Administration on Community Living, and the Administration on Developmental Disability, there is a big effort to look at data collection around developmental disability. It's a very specific question very often that people have in mind. The cognitive difficulty question. Those kinds of questions are not necessarily focused on people with developmental disability. And so it's a major issue. Please contact us if you're interested in learning more. We can send you links to some of the reports that were produced by ACL. Okay, I'm going to turn it over. Anybody else want to answer a couple questions that are live?

>> SHREYA PAUL: Yeah. I would like to answer a question by Hernissa. She says looking at the percentage across states could be risky as it does not account for the potentially larger number of people with disabilities in larger states like New York, Texas, and California. So, when we calculate the percentage, for say, employment or poverty, our denominator is always people with disabilities in that state. So, if we are saying that there are 25% people with disabilities employed in the state of California, we mean that 25% out of the entire people with disabilities in California. So, yeah. I think does that answer your question?

>> ANDREW HOUTENVILLE: Yeah, I think that's right. We stay away from reporting just sheer numbers. We provide the sheer numbers in the compendium, but when we start doing any kind of analysis, it's usually the percentage. And then we also look at the difference between with and without disability, specifically with employment, comparing some states who have better employment outcomes may be unfair. So, we look at and compare people with and without disabilities. Boy, a ton of questions. We have 27 open questions. Anybody else want to take a question? I'm tired of talking.

>> MEGAN HENLY: This is Megan. I can pop in here. Let me see if I can find it again. There was a great question here asking about how we plan to incorporate data from the decennial census. That's a great question. I don't know if anybody recalls filling out their census form about a year ago almost. There were actually no questions on disability in the decennial form this year. We've been using data from the American Community Survey. It's a sample survey. So, it's unfortunate that it does not actually count every single person, but it used representative sampling so we could capture good estimates for many different geographies and it does capture disability. It's more current. It's unfortunate we won't have the full population estimates, but we have current data and it will be updated every year, which is a benefit of that. So, I just saw that question and I thought I'd pop on there.

>> ANDREW HOUTENVILLE: Yeah. I just saw a question about data related to depression. Certainly psychiatric disabilities are not very well represented in a lot of the data products, a lot of the surveys that we're using. It's been improving over the years. The survey of income and program participation, the SIP, is probably the best most comprehensive national one, although it's not updated every year. It's updated roughly every four years. And so again, a lot of these are challenging. That same person asked, you know, are there questions that are better than others? We have a whole set of research projects that look at the way which disability-related questions are asked in surveys. And some are better than others. There's a fairly standard six-question sequence that's asked in most federal data collection systems. There's also the Washington Group set of questions, which comes out of the United Nations that is quite different. It addresses a lot of the same aspects of a person's life, you know, vision and hearing. But it allows Census Bureau and many other things say yes, no, do you have something or do you not? The Washington Group has a scale that you can respond to so that it's not just strictly yes/no. All right, anybody else want to take a question?

>> MARISA RAFAL: This was kind of related. I saw it in the Q&A. Any thought of using a different definition of rural? The OMB may undercount the population. The federal office of health policy may have a more useful definition for future analyses. I imagine we would have to talk it over with collaborators, but it is something we update every year. It's something we could consider. It's tangentially related because the way you count things and estimate them are going to affect your product. Definitely something to consider. And you'll see on Friday we pulled from several different sources for our infographics. They're definitely a compilation and there is flexibility there.

>> ANDREW HOUTENVILLE: Yeah. One that popped up. Many times you can look at the answers. There's some really fascinating questions we've been answering just by typing. Many people have talked about rural statistics. We have the rural section that we co-sponsor with the RRTC at the University of Montana. They have a lot of great products and I would point folks interested in rural-related transportation-related statistics, go speak to our colleagues at the RRTC at the University of Montana. It's the Rural RRTC. If you typed in "Disability research Montana rural" you'd find them. Google is probably the best way to go. If we can't send you. Or contact us and we'll send you their contact information.

>> MEGAN HENLY: And Andrew, I'll just pop in, just as Andrew noted in the question and answer, he also commented with contact information for RRTC Rural. So, if anybody has that handy, it's also just RRTCrural@mso.umt.edu. And there's a phone number there, as well.

>> ANDREW HOUTENVILLE: Yeah.

>> MEGAN HENLY: Lots of great questions. And I wanted to offer a quick comment on recent questions. Somebody looking for data on higher education did not provide their name. But please, I would love to be in contact with you if you have specific questions. There is data in the compendium on educational attainment, but nothing on current post-secondary enrollment. But that's something that we are talking about right now and we are looking at. So, we do have some data on that that we can provide if you just let me know specifically what you're interested in.

>> ANDREW HOUTENVILLE: Yeah. Kate just put it in, in the chat, I think. Or somewhere. Some information about costs. Annette, what do you think Annette? Some self-serving questions. Cost of disability, disability-related costs. We don't really have a good annual source of that. Actually, the medical expenditure panel survey would probably be the best. I'd love to see the consumer expenditure survey add the six questions. They should be. But that's the primary household expenditure survey in the United States. I'm not sure how they've gotten away with not complying with the ACA mandate to have, perhaps because it's not a health survey primarily. But the consumer expenditure survey would be that. Some folks have said have we used data from various foundations such as the Cerebral Palsy - United Cerebral Palsy Foundation. We typically steer clear of that. Only because we, you know, it has to be updated, it has to be publicly available. The developmental disability administration, if there's data that people think, if it's available, you know, on an annual basis, we'd love to do that. The 14C, someone asked about the employment. 14C, I just saw some really cool data. It's kind of hodgepodge data on the requests for 14C waivers. It could be done by state. It's this kind of cheesecloth Excel file that the Department of Labor puts out. I'm not sure how frequently it's updated and that would be really cool to, at least by the time we get into the compendium, 14C might be gone. 14C is the minimum wage exemption for people working in certain disability-related employment centers. Anybody else want to take a question?

>> SHREYA PAUL: I would like to take a question by Joseph Barry. He wants to know about the intersectionality of the data that we have in the compendium and the supplement. So, currently, we do have race, gender, age by disability type. For example, we do report on race by disability type. White Hispanic population with hearing disability or cognitive disability and so on. But this space can be explored more. And that is one of the notes that I would make for next year.

>> ANDREW HOUTENVILLE: Mm-hmm. Mm-hmm. Great. We are coming right up at 1:15. I am going to close. We will stay on to try to answer some of these live. So, whoever is running the show, you can stop recording, but leave it open so that we can answer some of these questions that are still going. And people can feel free to stay on to look at whether their questions are answered or not. With that, I'm going to thank all our speakers. I'm going to thank Phil Beatty from NIDILRR. And I want to remind everybody that we have our session tomorrow. Yeah, tomorrow, at noontime Eastern. We're going to be hearing from our federal data collection partners. And there's been a lot going on with data collection and adjusting to COVID life. Because the Census Bureau, when it sends people out or calls people, has to address the changing environment that COVID has really kind of impacted us all. With that, I'm going to say good-bye and we're going to stop recording. Thank you all. There's also an evaluation survey. I keep forgetting to plug the evaluation survey. You would get it on the way out. Disabilitycompendium.org. And that's where you can provide input on things that we should possibly include in the future as we expand the compendium and all our other products. All right, thank you very much, everybody!