

Elevating Rural Disability Data for Policy Impact

Transcript

2:30 PM – Opening Remarks

- **Susan J. Popkin**, Institute Fellow and Codirector, Disability Equity Policy Initiative, Urban Institute

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>>**Susan Popkin**: I'm Sue Popkin, institute fellow and co-director of the Urban Institute's Disability Equity Policy Initiative or DEPI. I'm an older white woman with salt-and-pepper hair. I am wearing glasses and earrings and a green scarf and a green jacket. I am a disabled researcher. I have Sjögren's disease - autoimmune disease. DEPI is working to build a body of evidence to improve the lives of disabled people. We aim to equip policymakers and practitioners with the rigorous timely and actionable research they need to advance economic mobility, housing stability, community connections and a more accessible and equitable public safety net. We are very excited today to be collaborating with our colleagues from the University of Montana research and training Center on Disability and Rural Communities or RTC Rural and we are looking forward to an exciting conversation today. I have a few logistics to review before we get started. CARD services are providing real-time closed captioning. ASL interpretation is also being provided throughout the entire event. This event is being recorded. The recording will be shared following the event. Audience members are muted, please use the Q&A box to ask questions to our panelists at any time. We have reserved time at the end of each panel to ask some of these. I am very pleased to welcome our five panelists, who will discuss priorities for ensuring rural disability representation across all levels of data collection. And this conversation takes place in the context of a larger discussion about limitations of the existing measures of disability in the American community survey and about the proposal to replace these questions with the Washington Group short set questions. Many researchers and advocates including those here at urban have called for more research to develop better measures of prevalence. The Census Bureau has listened to those concerns and has paused those plans for now. You could see some of the research links on our event page. We have an opportunity today to contribute to the national discussion highlighting the important, but often overlooked intersection of rural places and people with disabilities. Our conversation today will be split into two discussions. First, we will invite two panelists to share their experiences as disability researchers working with real-world disability data with a focus on disability measurement and data collection. And second we will visit with three panelists who use data in their work to elevate rural people with disabilities. And for our first panel, I will turn things over to my colleague Corianne Scally.

2:35 PM - Strengthening Rural Disability Data

Rural disability researchers will share current challenges to understanding disability in rural contexts, proposed innovations in measuring disability, and potential challenges to navigate along with increasing opportunities for measurement.

- **Kelsey Shinnick Goddard**, Research Project Coordinator, Research and Training Center on Independent Living, University of Kansas
- **Andrew Myers**, Project Director, Research and Training Center on Disability in Rural Communities; Member, 2030 Census National Advisory Committee
- **Corianne Payton Scally**, Senior Fellow, Urban Institute (*moderator*)

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>>**Corianne Scally**: Thank you Sue. Hello everyone, I am Corianne Scally. I am a researcher at the Urban Institute where I work on policy relevance and equity focused research including work on rural communities and people with disabilities. I am a white woman with shoulder length brown hair and an increasing amount of white hair

and I have invisible disabilities. I am very pleased to moderate this first part of our conversation today on strengthening rural disability data with two researchers, who work university centers focused on rural and disability research. I will ask them to join us now. Andrew Myers is the project director for the research and training Center on disability and rural communities at the University of Montana, our partner on this event. And Kelsey Goddard is the research project coordinator for the research and training center on independent living at the University of Kansas. Thank you both for being with us today. You can find out more information about their work by checking out their full bios available online. And as a reminder please enter your questions for the panelists at any time into the Q&A box and we will be reserving the last few minutes to try and address as many of those as possible. All right! So to get us started you both spent significant time working with and analyzing disability data from a range of data sources. My question is why is it so hard to get good data on rural communities? And Andrew, let's turn to you first.

00:10:53.000 / 4:39

>>**Andrew Myers:** Hello Corianne and thank you for having me. Yes, my name is Andrew. I am a white man in my 30s with short hair and some facial hair. Yes that's a fantastic question. So I have three things I would like to bring up. One is about definitions, one is about data, and one is about places. So there are more than a dozen different federal definitions of rural and depending on what you use, you might get anywhere between 72 and 97 percent of the total landmass or 14 to 20 percent of the total population. And it's important to also note that the concept of rural is not actually defined in most datasets. So the actual definitions of rural are actually what's called nonmetropolitan which we interpret as rural. There are also typically deficit-based measures. So whether it's lack of population or lack of economic activity it's usually defined by a lack of something. So in many ways I like to think of it as rural is like a non-geography. I am a geographer so it's not really defined. It's really the urban leftovers that we work with. It's also important to know that each definition uses different boundaries and different metrics. So some of the boundaries might be census tracts or counties or what's called urbanized areas. Some of the metrics are things like populations, commuting patterns, or economic activity. And this is important because this means that a place can be urban in one definition and rural in another. So there is a little bit of subjectivity regarding which definition to use. But ultimately, it's usually determined by whatever data is available. And so, there is really no single data set that includes all of the information that we might want as rural disability researchers. This means we have to link across different datasets, which can be complicated when we are doing data analysis to make sure the data still match well. So another thing to consider is the quality of data. And when I say data here, I am talking about quantitative data - numbers. It can be difficult to assess how well does it accurately reflect the reality of the ground, especially for rural disabled folks. The American Community Survey is one of the best datasets we have when we talk about rural disability data. But even there especially when we get into smaller geographies of very rural places the margins of error are very large and it's hard to do intersectional analysis. So when we are talking about like, disability and race, and gender - if we want to look at all of those things, it can be really hard because the sample sizes get so small even in a nationally representative survey like the ACS. I know Kelsey is going to talk a little bit more about that. Another thing to consider is rural places themselves. So recruitment and trust are huge issues not just in the U.S. right now, but especially in rural areas and in marginalized populations. Rural areas have a long history of exploitation and disinvestments. There's lots of hospitals that are closing and healthcare centers that are closing due to that disinvestment. It also means that recruiting study participants and collecting data in rural areas and among populations and people that have long been underrepresented is really hard and it's getting more and more difficult. I also want to point out that rural areas do have unique strengths. For example, informal relationships and shared values among people that folks with disabilities rely on daily to meet their needs. These are things like social capital, human capital, these are unique rural resources that are just not captured in national datasets. So with that I am going to cut my time and pass it onto Corianne and or Kelsey.

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>>**Kelsey Goddard:** Yes, thanks Andrew. It's great to be here. I am Kelsey Goddard, I'm a white woman in my 30s and I use a wheelchair. I live in a rural area outside of St. Joseph Missouri where poverty and disability are deeply interconnected. St. Joseph has a long history rooted in both agriculture and industry and many people in my community work physically demanding jobs in these sectors. Unfortunately, the strain from these jobs

frequently leads to long-term disabilities, both physical and mental, which I continue to witness firsthand. The lack of adequate compensation, lack of healthcare, and lack of paid leave in these industries only makes things worse, causing stress, anxiety, and depression to rise alongside physical injuries. This cycle of poverty and disability is made worse by the fact that we often lack the data needed to fully understand the challenges facing rural communities. While national surveys are crucial tools for gathering information on health and disability, they frequently overlook important rural specific indicators. For example, questions on healthcare access need to specifically address the distance and time it takes for rural residents to travel to medical providers. Surveys should assess the availability of transportation asking whether rural residents rely on personal vehicles or community networks. Data on social support systems should include how often residents rely on informal caregiving networks like family or friends due to the absence of formal caregiving services. And surveys should also assess broadband access for telehealth or telework, asking if residents have reliable Internet and whether poor quality or lack of access affects their access to care or employment. However it's important to recognize that not all rural communities are the same as Andrew was talking about. Rural areas can differ greatly in terms of economic base and infrastructure and social networks. So for example some rural areas may be built around farming or ranching while others are industrial or more tourism driven. These variations mean that the challenges faced by people in one rural community might be completely different from those in another. Yet current data collection methods often fail to capture these important distinctions. By treating rural areas as a single uniform category, we miss the nuances that make each community unique, further limiting our ability to create policies that effectively address their needs. On top of that even when efforts are made to collect rural specific data, they often fail to reach the most remote and marginalized populations. People with disabilities in rural areas are particularly hard to reach because surveys often rely on standard contact methods like phone or Internet. Which may not be readily available or accessible to them. Many rural residents with disabilities face challenges like unreliable Internet access, lack of cell phone service or physical barriers that make it difficult to travel to locations through surveys are conducted. Additionally people with disabilities may require alternate formats or assistance to participate in surveys but these accommodations are rarely built into standard survey protocols. As a result people who are already struggling with access to healthcare, transportation, and services in rural areas are often left out of surveys altogether. Their experiences which could inform much-needed policy changes remain invisible to researchers and policymakers alike. The exclusion of rural populations from national surveys results in significant gaps in our understanding of the challenges they face. Even when these data are collected there's often a lack of contextual understanding and how it's interpreted. Many researchers and policymakers are based in urban centers and may not fully grasp the unique realities of rural life. This urban-centric perspective can lead to misinterpretations of the data or policies that don't address the specific needs of rural communities. So in the disability community, we say a lot of time "nothing about us, without us". But as rural disability researchers we may add "if you don't know our land, you can't understand". And that's why how we measure disability is so important. Because without capturing these diverse experiences accurately the real challenges people face in rural areas remain invisible.

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>>**Corianne Scally:** Thank you so much. At a place called the Urban Institute we try and take a position of humility and partnership and really appreciate the opportunity to partner with researchers such as yourselves and ensure that we are doing our job in applying a rural lens to our work as it's definitely needed. Thank you both for your answers. I think you really captured the growing recognition that current methods of measuring disability, particularly in rural places are inadequate, and are often leading, unfortunately, to a further lack of inclusion and representation in the data that is being collected. Fortunately, there is an exciting and important national dialogue happening right now around disability measurements. So Kelsey, we will go back to you again first. As a person with lived experience in both the rural and disability space and a researcher, how do these conversations that are happening today matter for rural communities? And can you share some concrete examples for us from your work and the research that you do?

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>>**Kelsey Goddard:** Yes, absolutely! So I think we were talking about why disability measurement matters so much for rural communities. We can explore this by considering two key reasons. So the first is that we need to

recognize that rural areas often have higher prevalence of certain types of disabilities such as substance abuse disorders or mental health conditions. So for example, rural communities recurrently frequently face higher rates of opioid addiction, alcoholism, depression, and anxiety. These conditions are disabilities, but they are not always captured by widely used measures like the ACS6 or the WGSS so these tools focus really heavily on functional limitations such as asking questions about difficulty walking, difficulty seeing, difficulty hearing but they don't necessarily identify disabilities related to substance abuse or mental health. For instance somebody with PTSD and depression or addiction may not have functional limitations captured by these widely used measures of disability, but still experience profound disability. And so because these measures do not adequately address conditions that are common in rural areas entire segments of the rural disability population remain invisible in our data. Second, when disability data does not accurately reflect the prevalence or diversity of disability in rural communities our policies and programs will inevitably fail to address the specific needs of those communities. Without accurate data showing the extent of substance use disorders or high mental health conditions for instance, we might miss opportunities to invest in the right services. Like mobile mental health units, like telehealth programs or community-based addiction recovery services. So instead we end up with policies that are more suited to urban centers or that only address a narrow slice of the disability experience, leaving rural communities under resourced and underserved. And so this is where the work we have been doing with the national survey on health and disability or what I'll refer to as the NSHD, comes into play. The NSHD is conducted by the researchers at the University of Kansas and by myself and provides an opportunity to address some of these limitations in their current measurement tools. So our approach has been to explore new strategies for disability measurement that are more inclusive and representative of experiences including those of rural residents. And we have implemented a few key strategies that I want to highlight today. First, we have incorporated what we call a broad net question. So instead of just asking about specific functional limitations, we ask broad questions such as do you have any tip of health condition, mental health condition, or disability that has lasted or expected to last six months or more? So that question really helps capture people with disabilities who may be missed by more narrow measures. And then second, we allow respondents to self-categorize their disability from a list of broad categories. So that method offers people the opportunity to choose the category that best aligns with their lived experience whether it's a mobility disability, mental health condition, chronic illness, sensory impairment or another category. So that approach recognizes that disability is diverse and multifaceted. It ensures that people have control over how their disability is represented in their data. And then third we allow respondents to provide open ended descriptions of their disability to really empower them to describe their disability in their own words. So our research and the work of others here today like Andrew and Sue has really demonstrated that these more inclusive approaches to measurement provide a fuller picture of disability. When we get disability measurement right, we can better understand who is disabled, where they are, and what they need.

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>>**Corianne Scally:** Thanks so much! Great food for thought. A reminder to folks to please drop questions into the Q&A box. We will be turning to your questions shortly. Andrew, I would like to turn to you.

With new opportunities, often come new challenges. What are some potential challenges that we will need to navigate along with these opportunities that are part of the national discussion today?

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>>**Andrew Myers:** Thank you for the question. Yes. So we know as Kelsey demonstrated and discussed disability is kind of hard to measure. You know? In national surveys. And so is rural. You know? It's got a lot of nuances there. But it is absolutely critical that our conversations about disability measurement to include rural perspectives in that. And we need to be able to communicate why we need improved measures of disability and how that's connected to rural definitions. And as Kelsey mentioned part of that is because disability is more prevalent in rural areas. And one way to try to address that is we could include rural urban indicators in data while still omitting the specific locations. So that is one way of kinda providing enough privacy in some of these smaller locations while still providing enough data to do rural urban analysis. It's also important to know that the disability measurements we are working with right now are not great. They are fairly old. And so there is a growing discussion that we need a better measure of disability. And there has been efforts to improve those

measures. But we also need to be intentional that we don't throw the baby out with the bathwater. We need to make sure that we have overlapping time periods across datasets to ensure continuity of data. And that's a bunch of economic jargon to basically say that we need you know five years of data collected in rural areas to ensure that we provide accurate estimates. So when we work with rural data from the American community survey you need five years of data collected across time to get one observation because the populations are so small. So if we change a definition or something in ACS and we don't have any overlapping or transition period we lose all of those historical trends. And this happened in 2008, when they changed how disability was asked in the ACS. So for many years we did not have any longitudinal data. Or actually not longitudinal data - We didn't have any trend data about disability in rural areas for a very long time. My colleague Lily Brigan was the first to put that together when we finally had at least 10 years of data. So if you want to do a time comparison with ACS data in rural areas, you actually need 10 years of data to do it. You need one five year observation and another five year observation. So if we make these changes without being intentional about how that impacts our ability to track trends in rural places, or data collection takes a lot of time we just need to be cognizant of that -the loss of historical trends - and ensuring that there is some amount of data continuity there. Another aspect is I touched on this already little bit. But we really need to increase trust about data and data surveillance with rural communities and people with disabilities. I mean, the most recent example is when the Census Bureau proposed changes to the disability measurements. And it took a lot of folks in the disability community and disability research advocates by surprise. And there's been a response to that. You know? The Census Bureau is hosting a convening meeting. I think it's next Monday. But the point that I want to make is that too often data happens to people. It happens to communities, rather than with communities. And that goes back to kind of my point about exploitation. A lot of times data is extractive, right? It's pulling something out of the community rather than doing it with them. And this is important because rural is an underrepresented group. And so are people with disabilities. And so when we try to look at data when we are working with the intersection of multiple marginalized identities whether it's gender or sexuality or race and to bring in other aspects like rural or disability it's really hard to do those things. And so what I think kind of needs to happen is begin building those trusts in communities. Especially in rural areas and tribal communities. But that takes a lot of time and resources and it doesn't always lead directly to grant deliverables. A lot of time grant timelines are not actually that long. Some of them can be. But some of them are like, five or six years and there's a good reason for that. At the same time if you want long-term outcomes you kind of need long-term stable funding. And so what I would like to see is research agendas and review panels that see the long-term value in prioritizing that type of community work. It's often messy and sometimes improvisational.

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>>**Corianne Scally:** Thank you. Appreciated how you not only highlighted that we need better data but we also need a disability forward lens to ensure that we are both collecting and interpreting the data that we have as inclusively as possible. And so thank you for those insights. And the last couple of moments that we have left here let's turn to just a final quick question for both of you. As we have been noting we are at a pivotal moment where conversations about disability data and equity are taking center stage. From your perspective if you had to pick just one -what is the most pressing rural disability data priority that you would like to see on the national agenda? And we will just get a quick sentence or two from each of you. Kelsey why don't you go first?

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>>**Kelsey Goddard:** Yeah. Well, if I had to just pick one, it would be the need for rural specific metrics that truly captures the unique challenges of living with disability in a rural community. It's not just about asking more questions, it's about asking the right questions. Questions that reflect the distance people have to travel for care and reliance on informal caregiving, the lack of broadband access. Because it's not just about collecting numbers, it's about understanding the lived experiences of people, whose stories often go untold. And when we have the right data we can create policies that reflect realities of rural life ensuring these communities are no longer invisible in our national health and disability conversations. Because it's time to recognize that every community, no matter how remote deserves to be seen, deserves to be counted and deserves to be invested in it.

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>>**Andrew Myers:** I totally agree Kelsey. I'm gonna build a little bit on that but I'm gonna go back to numbers. I would really like to see disability included as a demographic trait in the decennial census. If we do that in the decennial census it means we actually get a real count of disability which is important in rural areas so that way we are not just using estimates like those in the ACS, which we know are prone to error, as good as they are. That also includes moving beyond measures of disability as just functional impairment. And moving from what I know Bonnie has called, Bonnie Swenore, has called a deficit-based measure of disability to more asset-based measures of disability. I will leave it right there.

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>>**Corianne Scally:** Thank you. I appreciate how you crammed at least several different priorities each. Well done, well done. Great, now we are going to turn to our audience and see what questions folks have submitted for you both to consider. We have had a lot of great questions come in around disability measurement and best practices for using data that we have available to us. I know you have both pointed out some pretty significant shortcomings and Kelsey there is a lot of interest in the survey that you administer as well. But what is the best practice kind of making do with what we have today? We will start there. For those who cannot go out and collect their own data. Any advice?

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>>**Kelsey Goddard:** I mean, my plug is going to be connect with us at the national survey on health and disability NSHD. I have shared that in some of my answers and I am a little slow at typing sometimes. I appreciate your patience as I get through those. But we do have the luxury of asking really nuanced questions about disability and about rural specific indicators. And we have a data analysis team that we host and engage with researchers across the nation. So I would love you know to have your involvement in that way and the more collaborators, the better. We would just really invite to explore really rural specific issues you know in some of those conversations.

00:36:15.000 / 29:55

>>**Andrew Myers:** I will chime in a little bit and focus on the ACS and the disability measures there. There is a lot of research going on about how well those different measures perform across different indicators. Kelsey and her colleagues, Jean, and Noel have been using NSHD to look at that and I think they are really informative. Like I said, the ACS six questions is limited as they are still provide us that historical perspective, which I always come back to. Like, we need to improve. But we also don't want to get rid of those historical trends. As a rural researcher, those are important because it takes time. And as far as best practices go for like, working with some of this fuzzy data, especially when you are looking at large margins of error- a rough estimate is like if the margin of error is larger than the estimate than maybe you don't use it or have a very large asterisk next to it saying this is the best we have but we also know that it's limited. So it really comes back to what Kelsey said which is that you still need that on the ground knowledge. We need to build those relationships because the last thing you want to do is go work with the community and have data that does not reflect the reality. So you really want to keep that in mind.

00:37:35.000 / 31:20

>>**Corianne Scally:** I love that advice. And, you already kind of started to enter this next question just to plumb the depths here. For folks in the audience, who are policymakers, researchers, practitioners, you know, trying to use and rely on existing disability datasets that we have - what caveats or advice would you give them to making sure that they are approaching the data as best that they can and as thoughtfully as they can? Again, you already showed a couple of examples. But if there's anything else you have to offer for folks that are doing their best to navigate available data and use it in their decision making?

00:38:58.000 / 32:12

>>**Andrew Myers:** Want to go first Kelsey?

00:39:00.000 / 32:14

>>**Kelsey Goddard:** I will just say, it goes back to the conversations of being sure to include people living in rural areas. I mean, again it's in our nature if we are working in these urban centric research centers or you know, working with urban centric policymakers that we don't really know all the nuances of what it means to live in a rural community. And so, yes. I would just highlight in those explorations, the importance of really collaborating with rural researchers.

00:39:18.000 / 32:53

>>**Andrew Myers:** Absolutely. Yes. Sometimes I'm gonna try and not use too much academic jargon. But one of the ways of scaling up your geography - rather than us looking at a small county, you might scale it to a larger area - so your sample sizes can kind of increase your scope, right? Like, if you are saying like I want to know what the data says about my community, but if the community is really small and the data is not really good enough to give you, like, a reliable idea of what is going on you may increase the size of where you are drawing those boundaries. Rather than working at the county level, you might scale up to the state level. Maybe you could say something about the state. That's one way of dealing with the sample sizes. I also think that my colleague Lily Brigan dropped in a really great resource that she's worked on called the disability counts. That website has like data that is pretty descriptive. But has often been used for kind of these kinds of things. The data is there available ready to go - you do not have to dig around in the data.gov up. Oh my God! What a nightmare. It's okay if you don't have to do it. But for most people, data.gov is kind of a black hole of information. So that's definitely check out disability counts.org. There can be some hopeful data projects there for you. Yes.

00:40:44.000 / 34:26

>>**Corianne Scally:** Great! Thank you for those insights and resources. We have had a great question come through. That I think you might have some interesting insights to. We talked a lot about measuring disability and thinking about how people with disabilities are captured and described in the data that we collect. But we've got a great question about caregivers. Where would you point folks to that are really looking for information about family care or informal caregivers to really understand the landscape there and their communities? And I know our next wonderful panel will be talking through this a bit. But if you have any suggestions for us here today.

00:41:47.000 / 35:32

>>**Andrew Myers:** Yes, that is such a great question and really I think hits the nail on the head when we talk about national data. That type of stuff is kind of hard to capture because it's relational, right? It's not a characteristic of a person. You are really capturing an interaction. And really those informal networks, which are not often standardized. Standardized data measures do not always capture the kind of stuff because it's messy and informal. Yes. I think the next panel will definitely speak to that. The one that comes to my mind is that my colleague Rena Sage has kind of done stuff around personal care and personal assistant services. I know she is working on looking at some need-based areas and looking at kind of how that looks on the national level to develop some measures of where that happens more than others. I'm not doing it justice in describing that. But it's a great question and I will see if Kelsey has anything to add.

00:42:52.000 / 36:36

>>**Kelsey Goddard:** I guess I'm a little bit more knowledgeable about the direct support workers and that kind of survey method. One thing that's been a little novel - I've been working on a project where we have been partnering with folks who do the electronic visit verification. It's like authenticator. And they have through their apps direct caregivers / support workers will have to sign into that system to kind of verify that they have been doing their paid services. So that is a dataset. I mean I will say a big limitation of that caregiver work force is that it is invisible. We don't have a lot of data about that workforce. A lot of states in the state of Kansas where I work there's not even a registry of direct support workers in the whole state. So we don't know who these workers are and we don't really honestly know a lot about them.

00:43:56.000 / 37:44

>>**Corianne Scally:** You have teed up a great challenge that I know our next panel is really excited to tackle as well. I would just like to thank you both for joining us today and just sharing your insights from you know, your deep experience in this work. Thank you so much. I am going to hand things back over now to my colleague so to introduce the next panel. Thanks.

3:10 PM - Elevating Rural Disability Data in Practice

Rural disability advocates and service providers will discuss the role of data in their work, how disabled people can be overlooked in data, and strategies they use to make rural residents with disabilities visible through more inclusive data collection, analysis, and interpretation.

- **Kiana Jackson**, Director of Data and Research, New Disabled South
- **Tafaimamao Tua-Tupuola**, State Director, University Center for Excellence in Developmental Disabilities, American Samoa Community College
- **Mary Willard**, Public Health Outreach Coordinator, Summit Independent Living
- **Susan J. Popkin**, Institute Fellow and Codirector, Disability Equity Policy Initiative, Urban Institute (*moderator*)

00:44:23.000 / 38:07

>>**Susan Popkin:** Thank you Corianne. That was a terrific discussion and really does queue us up very well for our next discussion. Which is going to be with rural disability advocates and service providers who talk about trying to do work on the ground print – what information they need and what information they do not have it, the compromises they make. I'm really excited to moderate this session with three great panelists to discuss their work - along using disability data to elevate the experiences of disabled people in rural communities. You will find their full bios online and learn more about their work. And as a reminder please keep entering your questions for the panelists at any time in the Q&A box and we will have a few minutes at the end to enter them at the end. In the second panel we pleased to welcome three different panelists from three different parts of the country. We're gonna start with Tafaimamao Tua-Tupuola the state director for American Samoa University Center for Excellence and Developmental Disabilities. Mary Willard from Summit independent living. And Kiana Jackson from New Disabled South. So really excited to have all three of you with us today. And I'm going to start with sort of a general question. Can you discuss the role data has played in your rural disability work and any challenges I'm sure you have challenges - you have experience in accessing or using that data? I'm going to start with Mary.

00:45:59.000 / 39:43

>>**Mary Willard:** All right thank you Susan. Again, my name is Mary. My pronouns are she, her, hers. I am a Caucasian woman in my early 40s with shorter length brown hair. In the background I have nothing about us without us handprint T-shirt. So I have had many different hats. I think all of them would be considered being a rural grassroots advocate. I am also a person with an invisible disability. Yes. I have used data in a lot of different ways. I will say that one of the most emergent ways we have used data it was during the pandemic. We you know, disability advocates across the country were really interested in especially people in congregate settings in rural areas. And I will just say that data was nonexistent. And it still is nonexistent. I also have used data - folks who work in rural areas need the disability data on people living in rural areas in order to grow and develop programs. We cannot better serve people with disabilities unless we have a good account of how many people with disabilities are out there. And we are not just really doing that yet. And then the other thing that I just wanted to add quickly. On the challenges on accessing and using the data because I think somebody earlier had mentioned you know, they want to be able to, as a grassroots advocate, be able to help get more data that is useful to the field. And I would just say that I think that was one of the challenges that we have as disability advocates is that the data is not necessarily usable. There has been some really great info put out. I think it was the rural Institute

that did this data disability briefs that break down data in a really understandable ways that then as advocates we can then take out and talk about what was going on in our communities. Not all of us are data and like survey research experts. So I think in order for people to be able to use that data more we need to break it down more. And I will just add that this is just Andrew mentioning all of the ways that we define it rural. And that couldn't be more right. I think something that I really found is that in rural areas disability looks different. I grew up super rural and not always do we think invisible disabilities are disabilities. That is something that I think we are working on. So I just feel like I loved everything that researchers were saying and there is a lot more to go. And I will turn it back to you Susan because I will talk on and on.

00:49:15.000 / 42:55

>> **Susan Popkin:** You can talk. That's fine. I'm going to give Tafaimamao a chance to talk about – something most people on the mainland don't think about - the issues of the data in those Territories. So I think we can all learn a lot.

00:49:25.000 / 43:12

>> **Tafaimamao Tua-Tupuola:** Good morning. I am Tafaimamao Tua-Tupuola. Tafaimamao in its entirety that really means a manifest vision in Samoan. I'm a Pacific Islander living in the Pacific territories, I have dark brown long hair. Wearing a long black and brown floral Samoan cultural dress, wearing a pair of headphones and a pair of glasses. I am referred to as she and her. I'm discussing the rural data as a Pacific Islander that would also require me discussing the geographic isolated data to provide a vivid image of not just the challenges but also the limited infrastructure and services for the disability to access. Whatever is available on the island. So think about the three Pacific territories. We are really located in the largest body of water in the world. And so in thinking about what does our infrastructure geographic isolated data look like. American Samoan poverty levels are 54 percent. We have seven islands. We have one hospital. Our CNMI poverty level is 38 percent and they have 3/14 islands of people live there. And Guam 20.2 percent poverty level, which is just one island. So imagine in a geographically isolated community, we don't have services available on an island, the data that you see in the census does not reflect the barriers that we go through on an island. At the end of the day the data that is really reported looks like just a regular number. So our population continues to also drop from the various disasters that occur in the Pacific region. The census 2020 reported that disasters are the fifth reason why Pacific Islanders move away from the Pacific territories. Now that's a problem and is a formula to drive appropriation for the territories. So that's another barrier. For household data in the territories American Samoan - 26.6 are multi-generational homes. CNMI 13 percent. So why is multi-generational homes so important? Because when healthcare or education or services are not provided on the island the entire family moves. The entire family moves. Imagine that. When they moved they moved to the mainland. The census reported that family related issues is the fourth reason why Pacific Islanders move away from their territories. And so this becomes problematic. Once we leave we do not return back home. So for a Pacific Islander we are really tied to the land. Our culture is not the only reason why it shapes our identity. It also ties to the cultural land here. So this is a driving force behind everything. So I also want to end with kind of talking about the tools and indices that utilize data, that excludes the Pacific territories such as the vulnerability indices. And when we talk about that how does this index that excludes the Pacific territory, address racial equity amongst the disability and aging community in the Pacific. So thank you.

00:53:41.000 / 47:28

>> **Susan Popkin:** Thank you. That was really interesting. It gave us a real perspective on the challenges. Kiana, do you want to talk about what new disabled South is doing and what the new challenges are there?

00:53:54.000 / 47:40

>> **Kiana Jackson:** Yes, 100 percent. My name is Kiana Jackson. I'm a black 26-year-old feminine presenting person. My pronouns are she her. I have locks in my hair. They are dark at the root and blonde at the tip. I am wearing a pink coral shirt and I have on glasses as well. I think one - I myself grew up in rural communities. I'm from Albany Georgia. I grew up in - I grew up in a community that has a lot of healthcare resources that a lot of people also don't have access to. I think a lot of times we talk about healthcare resources and the quantity of them. I think we need to talk about people's abilities to access them as well. And those are compounding things

that attribute to disability. One of the main things that I have encountered with doing disability data work, as an example, we do a lot of work around home and community-based service waivers and for most people, if you don't know home and community-based service waivers are essentially funds that states can allocate to people in this is a very generalized part of it. But funds that states can - waivers to get people in home services to keep people in community. And a lot of the work we do around that - we run into a lot of challenges with reporting on that. And this is largely due to inconsistencies. There is no standard in reporting on home and community-based service waivers. We will have some states where we will do a four year request which is a freedom of information act request and they'll give you everything that they have and then you have some states that don't collect racial data. Some states do, but won't give it to you. A lot of these very different states Georgia had two main waivers. Our first report that we produced on this was in Georgia. And we looked - we were seeking to identify or see if there were any racial disparities. And we found several. And we know that racial disparities exist in all forms of public health. And we wanted to see how they showed up in terms of people receiving services as well. And so in our pursuit of doing this research in other states we are seeing a dramatic difference in one the information that people are willing to share. Also the information that they collect. We have some states that have 10 or 15 different wait lists. A lot of times people get on these they apply to get on these waiver wait lists and they are we have talked to people that have been on these for 10, 15, 20 years waiting to receive services. Which is kind of the catalyst for us even doing this research into push state legislators to allocate more money to it. But then another thing that we saw in race was we have already encountered people that get off these wait lists and they get the waiver but then they don't have anyone to provide a service because there are a lack or shortage of service providers. So then that kind of lead us why is there a lack of service providers - so what we found ourselves doing is going down these rabbit holes in creating data points that just don't exist. And I think that is just one of the greatest challenges in doing this work in realizing this data does not exist and how do you create these data points when you are trying to maneuver state aggregated data while also trying to acknowledge the complexities that come with intersectional identities? I'm a black disabled woman. Born in the rural South. I sit at several intersections. I am a data point. How do we identify these nuances? It's the struggle and something that we also ran up against because one of the criticisms on us that we kind of got was out, y'all are talking about race and we don't look at race. But the a thing about every data point in healthcare is that race always plays a critical factor. It's one of the key intersections when it comes to access and outcomes. When it comes to availability and resources. And we kinda doing any disability work - find ourselves creating these data points and that's a key challenge in making data that just doesn't exist. And also realizing that data doesn't always tell the whole story. So I am a data scientist by trade. I love an excel spreadsheet. But also understanding these are not just data points, but these are also people in figuring out how do we tell these stories in a holistic way? That give credence to the data but also re-humanizes the people that we are in investigating or researching as well.

00:59:43.000 / 53:25

>>**Susan Popkin:** You have set us up perfectly for our next discussions. All of the issues around people not being able to see themselves in the data. Not having the data that you need. Really what do you do? Can you share an example of what this has looked like for the communities that you have worked with and what are the strategies that you have used to make residence in disabilities data visible? I heard what you said about creating the data points you need. But when we met to prepare all of you also talked about the importance of story and figuring out other ways to tell the story. So I'm gonna start with Tafaimamao this time.

01:00:19.000 / 54:03

>>**Tafaimamao Tua-Tupuola:** So I would like to say that there is more from a Pacific Islander experience. We don't just include it would not just be a disability but the entire family that evolves around the life of the individual with a disability. And that would be the unpaid caregivers, because of the necessary support that's needed throughout their life for those in need of long-term care and support. I think a lot of the unpaid caregiver data would contribute greatly. I think about how the unpaid caregivers also contribute to economic security in our own communities. I also think about the experience that my mom went through caring for my father and then her being an Asian caregiver. And when she would take my father to the hospital for a regular checkup what the doctor said to her stood out to me and that was having a disability for more than three years he asked my mother one important question. What does she do to take care of my dad for him to not have one single bedsore?

One single bed sore! And yet, that's the highest reason why older adults are hospitalized in American Samoa. And when it was time for her to - when my father passed on - and it was time for her to file for Social Security, she did not have enough Social Security credits. All of her years of caring for my father, keeping him out of the hospital, which we try very hard not to institutionalize. And in doing this as a family member, we're just only repeating the cycle and increasing the poverty rate in the territories when they are not counted. So I would like to see how can we elevate other unpaid caregivers reach out to other unpaid caregivers who contribute to economic security who contribute to the economic security but are not but are not really recognized for the economic support within their own community.

01:02:45.000 / 56:36

>>**Susan Popkin:** Thank you. Kiana, what do you do to try to make rural residents visible and how are you creating these data points?

01:02:59.000 / 55:46

>>**Kiana Jackson:** Yes, 100 percent! I think it is going back to I think several ways. So one I think it's changing the way that we view - how we view disability. I think especially when it comes to data and in research. A lot of times a lot of times the data you see around disability and the research you see around disability is from this really medical model. This really curing model. How do we eliminate these people from society? Just to be honest. And I think that we have to change the way we view it and focus on the experiences of disabled people and not a bunch of able-bodied temporarily able-bodied people. Figuring out how do we get rid of huge chunks of the population? It helps to know that one in four adults in America are disabled. Once the numbers are rolling out, once we see that trend change from people who are suffering from long COVID, once we see those trends we can expect for that number to rise. And then so it's going to be really important for us to start focusing on how we address that need status of disabled people. And that needs to be what's driving our research and data. Something that we did going back to our HCBS research, we focus on the services and lack of services that people have in Georgia. We identify the Georgia has a \$10 billion budget surplus. Looking at the budget surplus we in our report broke down and said hey, Georgia could actually fund every single one of these waivers for less than one percent of this budget surplus. For less than two percent of this budget surplus maybe less than three percent of this surplus, Georgia could actually give a raise to all direct service providers and move them from being paid \$10 an hour to \$18 an hour. Not only would this give people in the state something that is a legal mandate, we will get into it a little bit later I'm sure, but like, Homestead is a thing. And people have the right to be in community and the states are obligated to make sure that they are taking initiatives to do that. And so it's our job as researchers to identify when these gaps are happening and when the states aren't in compliance with making sure that disabled people are able to live and thrive in their lives. Another thing is that I think our data in our research has to move from just being so focused on aggregating in numeric data and more focused on the importance in the robustness that is qualitative data. Something that we have really focused on and incorporating in is sitting down and having these conversations and allowing disabled people to tell their story and not it being filtered through the mouths of people who are not living their experience. Lived experience is a data point. Qualitative data is important. Those stories are contributing to research. And I think that using those qualitative initiatives are efforts. In places where we don't have the data right. Our job is to go and create these. And so often we are looking for a table or a chart or really what we need to be doing is sitting down and talking to people and getting people's lived experience and navigating these systems. Navigating the nuances of accessing services and accessing care and allowing that to be this sort of drive for our conversations. Around all things related to disability.

01:07:14.000 / 1:01:00

>>**Susan Popkin:** Thank you. That was terrific. Mary, I think you also talked about the importance of asking people their stories and using those to tell the story and using those for disabled people in rural communities.

01:07:27.000 / 1:01:14

>>**Mary Willard:** Yes, this is Mary. I really appreciate what both my fellow panelists said. Tafaimamao Tua-Tupuola, you struck a chord with me. It's really about family and looking at the whole family. And I think that to

me is so rural. So I have spent probably 20 years in the rural independent living movement. And in the rural areas we are still talking about disability different. Some of my urban counterparts have this whole say the word hashtag disabled. And really taking that pride and saying that I am disabled because a lot of times it's the social environment disabling me. And what of the really rural areas the folks that I work with you know? We are still saying a person with disability because it doesn't - I'm just going to say that my friend Jim summed it up. He was a disability advocate in the rural area who told me that there was nowhere that he couldn't go as long as five of his friends wanted to go. And so just in rural areas I feel like we are so creative in just figuring it out. And I think Tafaimamao mentioned that. That's just how it is. A lot of people don't necessarily see themselves as having a disability or being disabled. But I want to mention a couple of things. One, that's why it's so important to let people tell their story. I think Kiana mentioned that too. Because you're gonna get so much more information sitting down with somebody and letting them share their story and then, you can start picking up on some of the language that might identify barriers, they are experiencing, or maybe hey, they do have a disability and they just don't know it yet. I think we have had folks in rural areas, when they were trying to go out and get surveys filled out they would just go to the community, sit down with people and fill their survey out with them. I think expecting somebody to take time out of their day to fill out a survey maybe it's not in their first language. Maybe they are not feeling like a strong reader or maybe it's not something that makes sense to them. So just going out and actually being in that community and having a presence is really going to help get better data in those rural areas. And then the other thing I just want to say there were a couple of comments again from grassroots advocates asking how they can help make data better. In the independent living moment - I started knocking on researcher stores. I'm grateful that there are a lot of really kind researchers, who saw the importance of having disability voices represented in the work that they are doing. But you know I invited myself to an AUCD meeting which is Association of University Centers for Disability. I started handing out my card and I said do you want disability voices in your project from start to finish? And I would say just start doing that. I would say the more that we show up and offer opportunities for researchers to continue to learn and get better data that's how we are going to, I think, break the cycle.

01:11:10.000 / 1:04:57

>>**Susan Popkin:** I like that idea. Engaging directly. Getting the researchers to pay attention. For our last question before turning to the audience and we are getting a lot of terrific questions again. To keep them coming. I'm gonna ask the same question we asked our first panel. From your perspective, if you had to pick one, what's the most important pressing rural data priority that you would like to see on our national agenda? I will start with Kiana this time.

01:11:46.000 / 1:05:28

>>**Kiana Jackson:** To me, the most important thing to me would be broadening the more widespread ramification of it - is the most recent Chevron decision and what the impact is going to be on the homestead. So the Chevron decision was a recent decision passed by our Supreme Court that kind of undid federal agencies right to kind of regulate enforcement and of these national laws and decisions, Homestead being once of them, and homestead, as I mentioned earlier, gives people the right to live in community. And I think that that to me is going to be a significant data point. Not just from a research standpoint but from a grassroots organizing livelihood standpoint. I think that there are so many harsh realities that are not far from existing with a rule like Chevron and it does cause me great concern to think about what the impact is going to look like on things like home and community-based service waivers and states feeling that need to make sure disabled people can live in the community. And to fund those waivers - we do not know - we don't know what the widespread ramifications of the decision are going to be. But I can assure you I know that there are going to be some pretty harsh ones. Particularly for us that live in the south. I think that that is going to really.

01:13:38.000 / 1:07:25

>>**Susan Popkin:** Can you talk a little bit about what you think might happen?

01:13:44.000 / 1:07:31

>>**Kiana Jackson:** Yes 100 Percent. I am concerned we are not as far away from forced institutionalization of disabled people as we might think. And if states feel that they no longer have to make sure that - or they have no responsibility - to keep disabled people in the community and make sure the disabled people have the resources to access a fulfilling life then especially as someone in the South social needs are not always - and are rarely a priority. And the thought that we no longer have federal agencies that can regulate that. That can have states meet a certain threshold that has a review process to make sure that this is a top priority - the enforcement of these acts in federal and legislative decisions to remove that power. To remove that review power of a regulatory body, that sets a standard or attempts to set a standard. It is extremely concerning. Because it could just be being in the South but I know recent Supreme Court decisions have not been in the best favor of marginalized and multi-marginalized communities and we see the effects of that every day on the news. And so I think to have a decision like this that removes a regulatory power in favor of hey we'll let the states do whatever they want to do and essentially when it comes to enforcement or abiding by these legislative and federal laws - it's extremely concerning. Especially when there's a decision that literally keeps disabled people out of institutions and mandates states to keep utilizing resources to make sure that disabled people can live in the community and can have a decision that says the federal government no longer has the same power to regulate this process as they once did. Given how dire our home and community-based service waiver and waitlist are - some states have 3000 people on these weight lists. The only thing keeping them would be, in my opinion, these type of federal acts. And now that we don't have any type of regulatory power by the federal government. I just shudder at the thought of what could happen and what will happen when we don't have that type of oversight.

01:16:35.000 / 1:10:26

>>**Susan Popkin:** Thank you. Tafa do you want to talk about what your most rural pressing data is for the territories?

01:16:48.000 / 1:10:34

>>**Tafaimamao Tua-Tupuola:** I think it would be a more equitable funding for the territories as I shared earlier that we are located in the largest body in the world. So imagine when we have to access healthcare, access education, or just have a conference in person and we always know that if an in person conference is available to everyone - imagine the cost we would have to budget just to be included. And with just one or two flights a week. But we are included. But the downfall is that the majority of our funding goes to addressing the inequities to be a part of the larger group. So there has to be a more equitable way of collecting data and interpreting data so that funding can be made and appropriated for the territories in a manner so that everyone can be a part of and we are not are not finding ways to be considered to fill in the gaps. We all know that we spend more money addressing inequities then we do then the remaining amount of funding left is really going towards the activity and so that is what we go through in many ways. And you know we have this we have this sayings as Pacific Islanders - "It's the ocean that divides us from being a part of everyone. But it's also the ocean that connects us." But what does it take for us to be connected? That's the gap. So I will leave it with that. Thank you.

01:18:44.000 / 1:12:35

>>**Susan Popkin:** Thank you! Mary, I'm gonna let you wrap up this question.

01:18:57.000 / 1:12:40

>>**Mary Willard:** Thank you. It's hard to follow both of you.

01:19:00.000 / 1:12:41

[LAUGHTER]

01:19:01.000 / 1:12:42

>>**Susan Popkin:** I know! [LAUGHTER]

01:19:02.000 / 1:12:44

>>**Mary Willard:** I just have to say something that you said Kiana really just sat in my gut and it was that we're not that far from forced institutionalization. Before I say what I want in data I would just challenge everybody in the audience, if you are not part of the disability rights community to go out and look up adapt and the free our people movement and learn a little bit about why institutions, why we are fighting so hard against them. I think - I don't know that everybody knows the story and that when people are institutionalized in a nursing homes or are incarcerated, you are more likely to die. It's more expensive to live in these places. So anyways check out adapt and look at our history of a disability movement and why we are fighting against institutionalization. And I just wanted to add to that that really brought to my mind - I'm gonna change my answer from our prep calls and I would love to see better data on rural people with disabilities during emergencies. Because when you said that when we are not that far from forced institutionalization, that really stuck with me because we were forcing people into institutionalization and we do all the time following emergencies. We saw during the pandemic. We see it following natural disasters that people with disabilities are forced into institutionalizations. I think for one reason because we don't have good enough data on them - we don't know exactly what is it needed out in the community during these disasters in order to prevent that. So I would like to see more data in that area.

01:20:59.000 / 1:14:45

>>**Susan Popkin:** Thanks to all of you and we have about 10 minutes for our open discussion if folks want to keep adding questions. I guess I'll pick up on what you said about emergencies. I see we have a forecast for one of our first big hurricanes of the season today. It hit Florida. And we know what happens when there's an emergency and people have to be relocated. Especially in a state like Florida when there's a large number of seniors. I guess I would like to hear from Kiana and Tafaimamao more. You mentioned emergencies and what does that mean and why is it important to have that information?

01:21:41.000 / 1:15:25

>>**Kiana Jackson:** Yes. So I am in Florida. Right in the eye of the hurricane.[LAUGHTER]

01:21:46.000 / 1:15:27

>>**Susan Popkin:** I am sorry to hear that.

01:21:48.000 / 1:15:29

>>**Kiana Jackson:** And that's actually most of my family is in Georgia as well which is also in the path of a hurricane. And so I think that these questions around like what do we do with disabled people during emergencies? I think it comes down to community care. I feel like we put so much on community when we have these sort of institutional things that are supposed to work but our government and things are supposed to work. But I think it really comes down to community care. As a disabled person, as a person who comes from a family of several people who are disabled, when we have these emergencies, I think it goes back sort of like this humanity, this humane part of saying who needs me most in this moment. What can I do best to keep this person best one surrounded by people who love them, surrounded by people who care. I know some work I did back in 2020, during the eye of the Covid pandemic. Florida was also a Covid hotspot. We did a lot of work around particularly in congregate settings. Work around providing care and PPE and food. We did a lot of grocery shopping for people. We did a lot of resourcing for people and we help people pay bills. We help people pay their utility bills and get their homes fixed up. We worked with community partners and we got grants and funding to be able to build. In the broader part we got grants and funding that helps build ramps so people can get into their homes and help modify people's homes so disabled people are not forced to leave their environment or their home. So I think it kind of goes anytime we see with the government fails, community tends to pick up and I think it just goes back to that. It goes back to that community care aspect and how do we build community care and this sort of interdependence in our nature as just human beings? How do we create this sense of empathy and shared concern? I think that's one of the main ways we do that.

01:24:21.000 / 1:18:09

>>**Susan Popkin:** Tafa - you talked about people having to move because of emergencies?

01:24:26.000 / 1:18:14

>>**Tafaimaao:** Yes. So our Medicaid actually covers transportation and that would also include air transportation. So if services are not available on the island. When Covid happened our borders were shut down for a whole year. And so that meant if they cannot get the Medicare or medical attention on an island they would literally charter a flight to take everyone who needed urgent medical attention to fly them out to Honolulu. So that also meant that as they have access to healthcare, they knew they did not have a return date. It was not clear when we would open the borders. So there were a lot of reasons since then, putting pressure on the government to open the borders. But I think that protected our community for two years because we knew our hospital could not handle the demand if Covid was breaking out in our territory. I also want to highlight that American Samoa was the only place in the world that was free from the Spanish flu. So when the Spanish flu broke out around the world, we also closed the border. So you could say that we were trying to repeat history and close the border again. Because there was so much unknown. So we also learned from what the world was doing in response to Covid. So this is what impacted our 2020 census because people were locked out of the borders when the census was occurring on islands.

01:26:21.000 / 1:20:10

>>**Susan Popkin:** Thank you. I think we got one question from the audience about a barrier that we always meet when discussing data collection in their state which is mostly rural this has to be a problem for all of you too - the problem with small sample sizes and identifiable health information being a privacy problem. Rather than accepting this as an excuse not to collect the data, how would you enable and empower public health data owners to help us characterize disability data statuses in rural communities? Have you any thoughts on that? How do you deal with the fact that protecting privacy and getting the broader information that you need?

01:27:16.000 / 1:20:55

>>**Kiana Jackson:** I think that there are ways to collect this data. I think though for me they are very creative when they want to be. And I think that's what we have to hold people to as well. It goes to I know one of the questions also we talked about. How do we organize communities to have that care? How do we organize these systems that are in place collecting this data to have that same care is a similar question. Care creates creativity. It breeds creativity. And you will get these government documents that have all of this information and they have redacted everything except exactly what you asked for. A lot of times when they say the data point does not exist, I don't think that the data doesn't always exist. I think it's a lack of willingness to share data that paints public health in a bad way. And I think that if our public health care system would not be so obsessed with their image and just cared about transparency we would have the data that we need. And I think what we have to start doing is pushing healthcare to be accountable to the public. And if you don't trust us with these numbers and you have a responsibility to give us these numbers in whatever way that you can. And that push doesn't always happen. It's like oh, we cannot give you the information and then we as community groups and advocacy group take on the burden to go on and say okay, we will create this data. But we are not the ones getting 6 million, 7 million, \$10 million grants from the government to collect this data either. The people, these institutions, these medical institutions, these medical institutes are the ones doing that. A lot of that is coming from public funds as well. So we have to hold our officials accountable. We have to start holding public health accountable for the information that they are collecting. And not just accepting oh, I cannot get that to you because of X, Y and Z. You can give me what you can but right now you're choosing to give me nothing. And I think that we can no longer accept nothing. We have to start pushing for transparency in public health, particularly when it comes to disabled people and particularly as disabled people are becoming a more broad more people are becoming disabled every year. Like I said, post Covid more and more people are disabled because long Covid - Covid was a mass disabling event. Disabled people need transparency in this moment. We need medical transparency, we need public health transparency, and we cannot as I said, continue to accept oh, we just can't give you the information. If you have it, there has to be some way that you can make it available. If you don't trust the public with the raw data, then you need to be regularly releasing things on the information that you are getting.

01:30:39.000 / 1:24:28

>>**Susan Popkin:** Thank you. Mary, I thought? Ahead. Go ahead. We have about a minute left.

01:30:48.000 / 1:24:30

>>**Mary Willard:** Perfect, this is Mary. I went back and read the question again. Sorry, I am a visual. But I think one thing that really sticks out to me is that they asked what can we talk to CDC and public health data gatekeepers to help empower them about disability status. I think they are looking at disability and health conditions as a negative thing. And I think this just goes back to again, the incredible work that we still have to do in the disability community to help people see that it's not bad it's not negative. Disability is a natural part of life. And I think that's the first thing. It is to really continue to change that script. I think the other thing is the small sample sizes. I think people understand if you are doing it right that they can select into the data, right? You can't force somebody to fill out your data. I think as long as you are explaining to people that the information might be out there and that their information may also help change their community for the better and if they still fill it out - I don't see what the problem is. I feel like that's just an excuse for the CDC to not gather data personally.[LAUGHTER]

01:32:11.000 / 1:25:56

>>**Susan Popkin:** Thank you. Tafaimamao any words before you close this out?

01:32:25.000 / 1:26:00

>>**Tafaimamao Tua-Tupuola:** No I agree with everyone and can I just say I think those in the community are at an advantage to collect the data from people who they are used to seeing on the ground. The territories are constantly excluded from outsiders trying to collect data. So we have this trust issue. So I really think that this is an opportunity for the boots on the ground within our community, who are familiar faces to take the lead in collecting data and we have a better way of analyzing. Thank you.

01:33:05.000 / 1:26:37

>>**Susan Popkin:** Well, I want to thank each and everyone of you for being with us today. This is a terrific, rich conversation that we obviously could've kept going with this conversation on rural disability and I think it's highlighted the importance of rural data and rural disability and the bigger conversation about measuring disability. The recording for this conversation will be available on urban's website in a day or so. And I think you have seen - I think Haley put in the chat that we have a survey that we appreciate people filling out afterwards to let us know how we did. Thank you so much, this was just a really terrific conversation - I know I learned a lot. We really appreciate you being here with us today!