INside the OUTcomes: A Rehabilitation Research Podcast

Episode 17: Disability Data Justice
Released July 9, 2024

SHARON PARMET, HOST:

On this episode of INside the OUTcomes, I'll be speaking with two very special guests about a big topic, data and people with disabilities. How are people with disabilities counted? Why do we need accurate data about people with disabilities? What is data justice? And how does data injustice negatively impact people with disabilities? These are just some of the questions I'll be asking Dr. Bonnie Swenor, the founder and director of the Johns Hopkins Disability Health Research Center, and Dr. Kate Caldwell, Director of Research and Policy at the Center for Racial and Disability Justice in the Northwestern Pritzker School of Law. Both Dr. Swenor and Dr. Caldwell have been involved in leading efforts to democratize the collection of data on people with disabilities. Welcome to the podcast, Dr. Swenor. And Dr. Caldwell.

DR. CALDWELL:

Thank you so much for having us.

DR. SWENOR:

Thank you really happy to be here.

SHARON:
So I'll just dive right in. I know that counting any group is a lot harder than it seems at first glance, and one of the reasons is that first you have to define who is a member of that group. Can you talk a little bit about how people with disabilities are defined when it comes to data collection?

DR. CALDWELL:

Of course. So one of the things from a research standpoint, is that the way you define something is going to determine how you study it. So if you're looking to gather statistics, for example, on a certain population, the way you're defining that population is going to determine what the population is. And so why this is important for disability is that disability is defined in a number of different ways. And a lot of them are using what's called deficiency models that see disability as something negative or something that's wrong or limited about a person that needs to be either fixed, eradicated or cured in some way. But there are other ways of defining disability. So an example of this would be, for example, federal agencies tend to define disability differently. So the Social Security Administration defines it as a work disability. So do you have something a disability that prevents you from working? The ironic thing there is that in order to qualify to receive Social Security Disability benefits, you actually have to work. So you have to gain work credits, and enough of them to qualify to, to receive those disability benefits. So even though you have to say you have a disability that prevents you from working, you have to work in order to get those disability benefits, right. So that definition prevents a bit of a Catch 22.

Another example that a lot of people are familiar with is how the Americans with Disabilities Act or the ADA defines disability. This one's really interesting because it has a three-prong definition, where you either have a disability, have a record of having a disability, or the third is you're regarded as having a disability. So if someone discriminates against you, because they see you as having a disability, you still are being discriminated against on the basis of disability, whether or not you actually have a disability, it's still disability discrimination. So there's these different definitions of disability, a lot of them are intended to be limiting in some way. And a lot of them drive the way that we're collecting data in the US. Whereas if you look at more expansive definitions of disability, for example, the UN Convention on the Rights of Persons with Disability or the CRPD, that actually has a more open definition that allows people to identify more freely as having a disability, and it's more in lights with a line with a human rights approach,

rather than like a civil rights approach, which is really intended to make sure that it's aligned with legislation and policy services and benefits systems.

And so these different ways of disability of defining disability are going to determine who gets counted as having a disability. But also, there's different ways that people define disability for themselves. So for example, there's this huge debate in the disability community between person first disability language and identity first disability language. So whether you refer to yourself as a person with a disability, which would be person first, or identify identity first, which is where you say that you are a disabled person. And from a research standpoint, I always see these as two different groups really, because there actually are a lot of people who have disabilities, but don't necessarily identify as disabled or see themselves as part of the disability community. So person first language or using that definition of disability is going to include people who have disabilities, but don't necessarily identify as disabled. Whereas identity first language is more of a socio-political orientation of people who do see themselves as disabled and or part of the larger disability community. And so I would see those as measuring two different populations.

SHARON:

So it sounds like it's extremely complicated to not only define disability but to determine how to count people who have disabilities. And part of the reason we need to know that numbers of people with disabilities is for benefits and for services and for the allocation of funding. And I know that recently, the US Census was considering changing questions on the American Community Survey related to disability that would have resulted in an undercount of the number of people with disabilities. Dr. Swenor, you led efforts, urging the bureau not to move forward with those changes to the American Community Survey. Can you tell us a little bit about that?

DR. SWENOR:

Yeah, sure. So, the US Census Bureau was proposing to change the questions that they were using to count disabled people or to identify people with disabilities in the American Community Survey. And so that shift would change from one set of six questions to another set of six questions. This movement was problematic for a number of reasons. The first is because as you indicated, it would have led to a drastic undercounting by 40% reduction of the national estimates of disability as compared to the current estimates, with the current questions that were being used are being used. The other big concern was that this proposed change really had moved forward without engaging the disability community, including disabled researchers or scholars, or people from the disability community. And that's a huge red flag.

And I think as Kate alluded to, disability is still a complex construct, perhaps maybe always will be. And the reality is, on the measurement side, we're not where we should be, meaning we have very limited tools, instruments sets of questions. So the offer on the table from Census to move from one set of questions to another. Let me be clear, our pushback wasn't because we think our current set of questions is ideal. It absolutely is not. Our concern is that the proposed questions, or the change they were proposing, wasn't including disabled people's perceptions and input, but also would lead to an undercounting.

So luckily, the Census Bureau has responded to that push back and has paused that change at least for some foreseeable future and has committed to engaging with the disability community. But it doesn't solve the issue of a need for better and more inclusive measures of disability that match some of the constructs that keep described, right, that move away from that deficit only framework because that's really all we've we have for the most part, and move toward them some more modern views, modern conceptualizations of disability, really, we don't have measures that match the way people with disabilities view themselves.

DR. CALDWELL:

And if I can actually add two things to that. The first is that this the six questions that are currently being used in the census, the ACS six that have about a 20% undercount. Currently, they're being used in 17 federal data sets. So this is a widespread problem. And if we were to change these to the new set of six questions that had a 43% undercount, then it would end up being reflected in all of those federal disability data sets. And it would be a much larger problem than just the census, right? So it's very big.

But the other thing is, they actually just successfully changed the question in this in the census on race and ethnicity, they combined it into one question. And the thing is, they actually spent over a decade working on this. And so what they ended up doing, is they let's see, they did in 2010, and Alternative Questionnaire Experiment. And then in 2015, a National Content Test, which included extensive focus groups, interviews and statistical testing of different question formats. With over 1.2 million households before rolling it out, and now they're finally changing it so that it's actually reflective and allows people to choose their race and ethnicity that most closely matches to who they are and how they identify. Why are they considering doing the same thing with the disability questions? And that's really I think all we're asking for.

SHARON:
Dr. Swenor, you mentioned that kind of, you're kind of looking for a shift towards more modern definitions and constructs of disability to enter into these questions related to counting people. Does the fact that people with disabilities as well have not typically been included in shaping the direction of where these questions are going? And what they're asking? Is that one of the things that goes into data injustice, I know, we talked on an earlier call about what is data justice? What is data injustice? Can you talk a little bit about that?

DR. SWENOR:

Absolutely. So data justice is this idea of how we collect, use and share data in ways that are focused on addressing the harms and injustices impacting people and groups in our society. It's an understanding that data are not agnostic. Data are powerful tools, they can be weaponized, and they can also be used to address inequities. So disability data justice is really applying that approach, that understanding to disability data, as we're really talking about, and recognizing that there is a really important bi-directional, two way relationship between data and society.

So data can either reinforce the biases and injustice is that disabled people face, or it can be set up and organized in ways to address them. But to do that, we have to make sure the data reflect the perceptions and the real barriers that disabled people face. And that can't be done unless we are working with the disability community and a diversity of disabled people. If we don't do that, and you're correct, that historically, that hasn't happened. And that leads to biases and honestly can deepen injustices of the past, right, a lot of the data and some of the ways that we're collecting data, including the example Kate gave, really are based on ableist ideas of disability. And again, it's that deficit model. And data, disability data justice is all about redressing that is all about changing that paradigm.

DR. CALDWELL:

I think one thing I'd like to add to that is that right now, you know, we are dealing with this the impact that the pandemic has had, and it will continue to have on our society as a whole. But one thing we really need to appreciate is that the pandemic has been a mass disabling event. And we are only just beginning to see the impact of that. And it's going to continue, especially as, as a society, we are now largely an immunocompromised population, given how exposed everyone has been to COVID-19. And when we're looking at decisions that are being made in policy and statistics that are looking at that are suggesting under counting a population that we're actually expecting to see an increase in as a result of this pandemic. That's supremely troubling. And it indicates a big concern from a policy perspective that I think is very much aligned with what disability justice is intended to accomplish in terms of ensuring equity, because we also are looking at not just people with disabilities, but also these intersections with other identity categories that are being hit hardest by any sort of emergency or disaster. Or any of these large-scale events, and how and they're going to be disproportionately impacting people with disabilities, communities of color, LGBT individuals, anyone living in institutionalized or congregate settings, disproportionately.

And so in order to actually make sure that we're echoed equitably as responding to what's happening in these communities, we need to actually be collecting accurate statistics so that we can so that we know what the impact is, because impact is, it's a quantitative term, that it's something that needs to be measured. And a lot of times we use it sort of as a throwaway term, but if you say something's having an impact on a community, that's something that needs to be measured. And we aren't going to be able to measure it if we know for certain we're under counting it, which is what we're doing now.

And so data justice and equity is really making sure that we are responding to the needs of communities that are being disproportionately impacted by negative factors by making sure that we are accurately measuring that impact.

SHARON:
What are some of the ways that we can improve how we collect data about people with disabilities? What are some solutions or ways to address this that you would like to see rolling out?

DR. SWENOR:
Yeah, so, you know, part of the path forward is a roadmap, I would say of change, right? We need some short-term goals, some midterm goals and a long-term goal here, because, as was demonstrated with the changes to race, ethnicity data, this is not going to happen overnight. This isn't going to happen this year. But we need to outline and start to get agreement on the path ahead of us. Right. So to me, that's what has to happen.

And what that includes is some structures built into that. And there's a view and conversations of what do we do with the data we have now that we know are limited? Do we abandon it? Do we not use it. And I always suggest a growth mindset on disability data where you use the data, you have to identify and address the inequities as best you can, as Kate described, but fully lean into and understand the limitations that you're dealing with. And be upfront about that and recognize what that does to your estimates to your analyses. Be realistic about that. Making sure you're using data to advance equity through a lens of intersectionality. And that you are sharing the data in ways that is inclusive the data you have now, right?

So there's a focus on making sure it's accessible, democratizing that data to make sure it's being shared with a disability community to inform decision making. It also means we need to start to build the foundations of including people with disabilities all along this roadmap at all levels, as researchers, as leaders in the federal government, as community partners and experts. Unfortunately, those relationships don't exist around this question, at least in enough spaces. So that is also I think, what needs to be part of a shorter-term goal.

I also think that a longer-term goal is actually what again, for race ethnicity, is we need to do the research, right? We need the funding to then do our homework, develop a more modern framework to develop better measures on do the testing. But that requires partnerships with the federal government funding from all sorts of sources, researchers and the community to get there. And then the long term, we would hope, I think, to get to a more inclusive data approach, that would be a standard, right, maybe getting closer to some more standard approach here on disability data, and making sure it's community informed and driven, to be honest, not just informed, and expanding the places we're collecting that data, we don't have enough data and enough places on disability to really address all the inequities we face.

So I know it's a bit of a long answer. But to me, this is a process, and we have to just be realistic about that process. I do want to just add, though, that in response to the pushback on census, there is now an interagency working group on disability data that has been organized, being co-chaired by people from OMB, the Office of Management and Budget. Leadership from NIDILRR, the National Institute on Disability, Independent Living and Rehabilitation Research, always got to think that one through, and the White House Office of Science Technology Policy, so well, I don't think we're at a place where we're gonna get to a standard like the working group for race and ethnicity dead. We can at least hope that that working group will help us get on that pathway on that journey on that, that, that place to develop a roadmap.

DR. CALDWELL:

And I agree with everything that Bonnie said, I think a couple of other issues.

One of the most important things is that we are not disaggregating data enough, and we really need to be disaggregating data by disability also by race and ethnicity and gender and LGBT status, because that is a huge

roadblock. I can, I'm hoping that's one of these things that this new Interagency Committee on Disability Research is going to be doing.

I think also there's a lack of centralized data. And hopefully, that's the purpose of this committee. And but also, there's also a lack of centralization of data from the state to the federal level. And so there's, there's things that are happening at the state level is very different from another states. But also, it's hard to make sense of, and it's not clear. There's also a difficulty getting access to data that should be publicly available. And so that needs to be more readily accessible to the public, as well as researchers. And instead, what we're kind of seeing is increasing roadblocks. We aren't seeing as many going up as during the Trump administration, where the answer to every request for access was been pretty much we're revising our decision on what data to make publicly available, we'll talk to you in the next administration. No, now at least we're hearing like, okay, we're working on trying to improve things. But it is still very difficult for researchers to get access to data that's being paid for with public funds, and especially in a disaggregated format that can be analyzed for the things we need to look for.

But more so if we're seeing things like what CMS the Center for Medicaid and Medicare Services is doing right now, where they're going to be charging tens of thousands of dollars to get access to their database. And so that's actually going to be preventative, especially for new young researchers who are coming up who don't have access to a lot of funds. But even for those that do have access to funds is going to be expensive. And so that's a concern.

We definitely need to be including more disabled researchers in disability research. And one of my areas of expertise is in entrepreneurship. And innovation is a big part of that. And in the innovation literature, we hear a lot of rhetoric and disability policy and policy in general about, oh, let's innovate, let's innovate. But it really is the superficial term that's getting thrown around. Innovation actually relies upon a creative, destructive process. In order to make way for new products, new things, and new ways of doing things, we need to phase out the old. But in the disability policy space, they're really bad at phasing out old ways of doing things. And that includes continuing to fund things they know don't work, or funding things in a way that doesn't allow for new ways of doing things to get funded. And a lot of it is because they take this very restrictive approach to funding disability programs, research and services, because they want to spend as little as possible, because there's the stigma that disabled people are a burden on society, and they aren't contributing, when in fact, disabled people aren't contributing, right? They're paying into Social Security, even when they're receiving Social Security, right, like, and so this the stigma behind disability and what it means to be disabled in our society is affecting disabled people on so many levels, including what's getting funded and what's not getting funded.

And there is a surprising lack of methods for disability research. Most of most of the methods haven't been developed specifically for disability studies research, or disability justice research, a lot of it's been adapted from more normative research methods to be used for disability populations. But those methods, those standards are very entrenched in medicalized and deficit models of disability. But a lot of the reason why we're lacking in new methods, new ways of doing things, new measures, is because we're not funding it. And so we it really does come back to actually providing funds for this and also making sure that we're providing funding, mentorship, professional development and support to disabled researchers who experience a lot of discrimination and barriers in academia, which is also an ableist institution in and of itself, I say, as a product of that institution, having to fight every step of the way. And as someone who was told people like me shouldn't go to college. And I'm now sitting here with a PhD talking with you both about the importance of actually making sure that we're providing opportunities for disabled people in this country.

SHARON:
Dr. Swenor, do you have anything to add?

DR. SWENOR:

No, I always love listening to Kate on these issues, who I think is well ahead of the curve in these conversations. And yeah, I agree wholeheartedly. We need we need them. We need to do the research and we need the support to do it and we need the people who understand the problems to be working on them.

SHARON:

Well, thank you both for being on the podcast. I've enjoyed talking with you and talking about data justice. And I hope to see you back on a episode in the future.

DR. SWENOR:
Thank you so much. This was a pleasure.

DR. CALDWELL:
Yes, thank you.

SHARON:

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host, Sharon Parmet, signing off.