



E04: Pursuing Economic Justice for People with Disabilities- With Rebecca Cokley, U.S. Disability Rights Program Officer, Ford Foundation

Voice Over:

Welcome to Let's Get to Work: Reimagining Disability Inclusive Employment Policy, brought to you by the Burton Blatt Institute at Syracuse University. And now here's your host, Michael Morris.

Michael Morris:

Welcome. This is our wonderful new podcast series, Let's Get to Work: Reimagining Disability Inclusive Employment Policy. I'm very excited today to bring you our special guest Rebecca Cokley, who plays a very important role at Ford Foundation, we'll be talking with her about that. But let's jump right in to some questions. Rebecca its glad to see you again, and let's start off with just talking about this unique position you have at the Ford Foundation that allows you to invest in un presidentent funding of activities. That's reshaping the participation of people with disabilities in our society, but most importantly, in the labor force that can advance their economic wellbeing. I know you're looking a lot at intersectionality, the intersection between race, ethnicity, gender, and sexual orientation. Can you share with our listeners your goals to change oppportunities for economic empowerment, for people with disabilities, and particularly those have been devalued and marginalized.

Rebecca Cokley:

Thank you so much, Michael. I like to say that I've had a history of having the best jobs in the disability community. So currently I serve as

the US disability rights program officer at the Ford foundation, which is the first role of its kind at Ford and largely across big time philanthropy, you could say so I manage a portfolio and the focus of our portfolio, or one of the major focuses of our portfolio is economic justice. We know that people with disabilities make up the majority of low wage workers. We know that people with disabilities are underpaid, underinsured, underemployed. If there is an under, we are the under and at the same time, we are disproportionately represented across other marginalized communities, whether it be communities of color, indigenous communities, among women, among LGBTQIA folks among immigrants. And so there's no way no policy that could be developed focusing on ameliorating poverty in this country, or frankly in the world that will ever be successful.

Rebecca Cokley:

If people with disabilities are not included and are not centered in that conversation. And that is really the forefront value of the grant, making that we're conducting over these next several years as we are, one of the first things that we did was bring the community to the table. We had over we over 150 individual conversations and a series of community based strategy sessions, talking to folks with disabilities, talking to family members, talking to disability, service providers and allies, talking to people with disabilities who don't work in the disability community or what I lovingly call the disability cabbage patch, as it were and said what should we be investing in? Where is the need? And what we heard time and time again, was working at getting at the nexus or the aura Boris, as you will, of disability and poverty.

Rebecca Cokley:

And so our grant making in our first year had a significant focus on that. The other, major focus is on building the field because we also know that we can't have the kind of change we need to have, or we can't drive the kind of change that we need to drive. We don't have advocates to push it. And so in year one of the things that we were really excited to fund is a grant to the century foundation, to my old colleague and partner in crime, Rebecca VALIS, who is working to build out a disability and economic justice Roundtable, bringing together leaders in the disability policy space with leaders, doing anti poverty work, actually sitting down to say, what does... How do we reformat or

reformulate Nutrition policy to better meet the needs of people with disabilities and their family.

Rebecca Cokley:

For example, most snap policies won't pay for you to have pre-cut or pre-cooked meals. And that is a real challenge for people with disabilities, for whom having, being able to go in and get cut up fruit is an accommodation, or being able to go in and get you wings or a salad that's pre prepared is accommodation. We are delving into looking at the issues facing native Americans with disabilities, who are disproportionately impacted by poverty. And so we're, pleased to be funding, gender and waters organization crushing colonialism, which is the first native led disability justice organization. And we see that as a key piece of the work as well. And so it's both about how are we getting to the policy areas that we need to focus on, but how are we also building up the people who are impacted by the bad policy?

Michael Morris:

Rebecca, let me take you from there to talking about the future of work, poverty is endemic to people with disabilities because people with disabilities are not in the workforce in the way they should be for you. How do you see the future of work, whether it's flexibility in terms of where you work hours of the day you work, maybe it's entrepreneurship. How do you expect the changes related to the future of work will impact people with disabilities?

Rebecca Cokley:

Well, I think there is no new normal, I continue to hear people say, well, as we get to the new normal, or as we get to post COVID, I hate to be Debbie downer or the disability community is Cassandra, but that's just not happening. I think we've seen it where disabled people and our allies have fought for flexibility in the workplace for decades. Since the ADA and even before the ADA. And so when I hear employers, continue to communicate well, when everybody's back in the office, eight hours a day, five days a week, and that's just not happening. And I think we're seeing not just people with disabilities, but people across the workforce broadly saying that doesn't work for me. Why does it have to be that way? And so the continued pushing for increased flexibility, isn't going anywhere.

Rebecca Cokley:

I mean, there jots the cat, there is an internet cat that is actively talking about workplace flexibilities. Once the cat start unionizing, I think we're all screwed, but it continues to drive home. The, conversation that work doesn't have, have to look work, shouldn't look the same in a post or in this next phase of COVID, as it's looked for the last 30, 40, 50, years, even before that. But it does mean that we need to see some changes and it means we need to, talk about both the good parts of the fair labor standards act and the challenging part such as, the creation of the sub minimum wage and continuing to drive the need for that to change. It means that we need to ensure that people with disabilities are included when the small business administration is talking about marginalized communities for small, targeted minority owned, small business grants.

Rebecca Cokley:

Whereas right now we aren't at the table. We aren't included as a group, but yet we, people with disabilities are one of the fastest growing groups of entrepreneurs. It means, really having the conversation around asset limits, which I'm really excited to see, continue to be part of the conversation. And I know Senator brown has been really committed to driving asset limit reform. And, in the last couple of months, we've seen both governors in California and New York really want to push to significantly raise asset limits for Medicaid in their states in such a way. I mean, we're talking about going from \$2,000 a month to like hundreds of... Or being able to have hundreds of thousands of dollars in savings. And that's going to be reality shifting for the disability community and some really key ways.

Michael Morris:

I know. And you've just started to talk about public policy change. When you think about the public policies and so many impact people with disabilities, what do you think are, particularly holding people disabilities back from being employed and economic advancement?

Rebecca Cokley:

I think that the conversation around how you must be, I think work requirements that we saw rolled out in a number of states over the last several years are really problematic, for so many people with

disabilities being forced to choose between full-time employment, whereas you may or may not be able to actually find a full-time job that accommodates you and meets your needs and your healthcare that's blackmail, that's extortion, and it needs to change. I think continuing to create pipelines for our young people. I can tell you one of the things that's terrifying me right now is what we're seeing happening on our college campuses. As students with disabilities are being told that the accommodations they had during COVID are no longer available are being told that remote learning is no longer a reasonable accommodation under law. When we've actually just come out of two plus years of it, and students are having to contemplate dropping out of college because they can't have, the services that they need.

Rebecca Cokley:

And it's ridiculous. I am terrified at the prospect of losing a whole generation of disabled college graduates because, all of a sudden, colleges don't want to provide accommodations that they've been providing for the last several years, or they're not willing to provide them going forward. And, that really is scary to me in this moment.

Michael Morris:

I know that with COVID, as you mentioned, we're not out of it yet. We actually have seen some increase in employment of people with disabilities, huge numbers of jobs, millions of jobs going unfilled. And, so I think we're beginning to see businesses looking at people with disabilities as an untapped group with talent and to be a part of their labor force. What, are you seeing from your vantage point and are there ways business culture can change even more rapidly?

Rebecca Cokley:

Definitely. I think that we are starting to see a shift and we saw it definitely numerically during the height of the coronavirus pandemic people with disabilities, many of we're already looking to work from home. Many of whom needed flexible hours, many of whom are also caregivers in their own right, for loved ones. And so, we saw disability employment increase significantly. I think as, as we move forward, there really is the opportunity for employers to actually sit and, it's salmon, what are the essential functions of the job and where can it

take place? The thing that I equally fear though, and this is always the challenge is how do we make sure that it's centered on what the needs of the employees are? So we don't end up in a situation, whereas I could easily see employers saying, well, great. If I hire a bunch of disabled employees, we can just have them work from home and not have to make our business accessible.

Rebecca Cokley:

We don't have to move into an accessible building. We don't have to, make sure that there's an elevator or, a modified bathroom. If all of our disabled employees are frankly segregated in their homes. And so how do we move this from an accessible or not, or an inclusive or not conversation to one grounded in like the universal design of work as we move forward?

Michael Morris:

The, I know, very much about how much social security roles hold people back with disabilities. And we see every year, a number of bills introduced in Congress. Unfortunately, most of them don't move. But from your perspective, what would you love to see change in our social security rules that rather than holding people with disabilities back, actually move them forward from an employment in economic sense.

Rebecca Cokley:

I would love to see a complete rethinking of work incentives for the, 21st century, like grounded in the 21st century grounded in this, new reality of COVID. I would love to see people who come off the roles for trial work periods, be to get back on the roles, if they need to, without starting back at the bottom, I would love to see significant reforms to continuing disability reviews so that if your disability isn't going anywhere, you're not having to continue to go through them. I watched my mom go through them. And I remember her going to see a doctor who had clearly never seen a person with dwarfism before and him asking her, so how long have you been like that? And she was like, you mean not being able to move my arms, which was the problem that led to her signing up for social security and being like, no short.

Rebecca Cokley:

And she was 43 years. And he was like, I've never seen that before. And I remember as a, young person at the time, I was involved in youth activism through, the national youth leadership network being like, are you, how are you qualified to do your job? Like to when, you've never, you're a social and you've never seen a person with dwarfism and you didn't know it existed. Like we have a problem here. I also though think Michael, that we actually need to invest in social security. We need robust investment in it as a federal agency. We've seen it, frankly, decimated as an agency they've had huge numbers of resignations and retirements, a huge lack of leadership across the agency, a lack of ingenuity and innovation across the agency. I would love to see social security become the model employer within the federal government, for people with disabilities and actually be shifted by the people that work there.

Rebecca Cokley:

I think, remanding all of these offices that have closed through the pandemic, social security and the post office to me are the two agencies and IRS are the three agencies that know how to find people that know how to touch that actually touch the American people. And the fact that it has been so chronically underfunded, it was practically destroyed under the last administration through multiple, or at least it was the destruction was attempted multiple times to actually sit and say, so what would reform to these programs look like, and we know what the low hanging fruit is what we've been argue about for years. It's, increasing asset limits, it's, eliminating some of these barriers to work for folks. But I think that there's so much more that can be done, particularly for, our young people, because I mean, to sign up on that program often than families will encourage them.

Rebecca Cokley:

Well, you can't leave the program because then you'll never have insurance again. How could we actually create a program that has mechanisms that allow our young people to thrive and to transition into work without immediately losing their healthcare? how do we, how do we on the medic, on the CMS side, how do we push for medic portability? I mean, I think we all know stories of people who got so many hours of HCBS in one state. I remember a young man who had a full ride to Harvard and had to stay in Illinois because in Illinois, he got

16 hours of home care. And in Massachusetts, he would've gotten four and his life is inexorably altered by the decision that he had to make. That's not fair.

Michael Morris:

The point you make about social security access to healthcare asset limits, these, are many of the areas that this new center, the center for study disability, inclusive employment policy will be working over the next five years funded by the national Institute on disability, independent living and rehab research, a group of researchers from Harvard, Rutgers, and Syracuse universities, this term disability, inclusive employment policy. I'm not sure lots of people understand what that means. What does it mean to you?

Rebecca Cokley:

To me, it means having Taran Williams as assistant secretary of the opposite disability employment policy at the US department of labor. The fact that OAP is now being driven by a black disabled woman is a powerful thing. And not just because she's one of my oldest friends in DC, and we started out together at IEL and I may have recruited her to be my boss once or twice, but it means disabled people who have been impacted by these programs and policies being at the table, driving the kind of change that needs to happen instead of having the change done to us. And then five years later being asked why things haven't changed.

Michael Morris:

I think this is a great segue to talking about Rebecca, what motivates you? you've had amazing jobs, white house, and now at, Ford foundation, what motivates and drives you and maybe there's lessons in that others in the disability community, whether, and particularly you talk a lot about youth to kind of raise their vision of what's possible. So what does motivate you?

Rebecca Cokley:

I think for me, I have a post-it note. That's been on my computer since my days at the white house. So it's been on probably or seven computers at this point. And it says, WWPMD what would Paul Miller do? And Paul Miller was a friend and mentor to me throughout my

entire life. I remember being a small kid, going to little people conventions and saying to Paul that I wanted to be a lawyer and him starting to send me briefs. He was working on, and I was probably like seven or eight at the time. And so he would, always check in with me and be like, "Hey, what are you studying? what are you working on? What are you reading?" And to just always be a presence in my life, like checking in, it was mentors like him and Curtis Richards and Richard Horn and others who are really instrumental to my development, and I think for me, I never could have imagined walking, working in the white house if I hadn't have seen Paul Miller do it.

Rebecca Cokley:

And one of my favorite things to do when I worked in the Obama white house was giving tours, specifically young people with disabilities and watching this next generation of young people come up and be used to seeing people with disabilities, working in the white house, are used to turning on CSPA and seeing members of Congress with disabilities like Tammy duck, or Senator Duckworth, Senator Tina Smith, representative, Ayana Presley, representative, Katie Porter, all of whom identify as part of the community is really powerful. about kids like Zara from little lobbyists who I talked to one day who called me, they were on their way back from a playground that they were told was accessible. And it wasn't. And I was like, Zara, how was the playground? And she was like, that was a playground.

Rebecca Cokley:

And I remember laughing so hard and I was like, well, why? And she's like, it was completely a next festival. They said it was, but there was no swing I could write on every kid with a disability should be able to go to their neighborhood playground and write on a swing. And it is ridiculous that 30 years, 32 years after the ADA, we're still not there. That is what keeps me motivated.

Michael Morris:

Well, let's, go back to one of the issue you mentioned, which relates to entrepreneurship and small business ownership. You're well aware and I'm sure many of our listeners are people with disabilities actually start small businesses way outside their, expectations of the general public. But I sure that government or the private sector have done enough

and to really encourage small business development entrepreneurship by people with disabilities. Do you have some thoughts about that and how can we do better?

Rebecca Cokley:

I would really love to see the department of health and human services come up with an innovation fund. We had, a innovation fund over at the department of ED when I worked for secretary Duncan. But to be able to say like, what are the things that people with disabilities need and how can we support disabled scientists, disabled innovators, disabled entrepreneurs. And it, I mean, why is it that so many disabled people continue to die because of bed source? Why do we have wheelchairs that can go upstairs? Can moonwalk, but cannot cure or prevent bed sores. And it's ridiculous to me, why don't we have prizes like the MacArthur genius for innovation and disability that would encourage not just people with disabilities to suggest ideas, but people with disabilities to actually solve problems. Why has it taken years to actually get an umbrella that you can Mount on a Walker or a wheelchair?

Rebecca Cokley:

I remember going to Disneyland with my dad when I was probably five or six, and having to like where the parka and drap a parka over him and eye and the battery pack that I was standing on the back of his chair, because we were afraid of the battery shorting out. Like, why isn't there an umbrella that just mounts to wheelchairs, like some of this stuff, why a wheelchair still ugly and not sexy when we have sexy cars like sexy wheelchairs, sexy rollators, sexy canes. I remember writing John Kemp one time because I had a staff person that needed a new cane. And he is like, I don't want a cane that looks like a medical cane.

Rebecca Cokley:

I remember writing John Kemp and being like John, you are one the most stylish men in the disability community. Where do I turn my staff people to find us sexy cane? And I remember him laughing so hard and be him being like, here are three websites to use Becca. And I'm like, why are we still having to fight for basic needs after all this time? And why isn't there funding supporting disabled entrepreneurs, disabled

innovators to create tools and we resources that would make the world better for everyone.

Michael Morris:

Excellent points, Rebecca, as you look ahead over the next five years, you will have an, incredible vantage point being at the Ford foundation, which of course looks not only at US, but worldwide. What, is possible in terms of economic gains for people with disabilities, whether it's achieved through working in competitive, integrated in inclusive places and workforces, or it's, as you just talked about entrepreneurship opportunities and possibilities, what do you see in, do you have a sense of optimism that the world will continue to change, but be more receptive and people with disabilities will continue to grow in their economic activities. And, as a potent economic force.

Rebecca Cokley:

I think I have to stay optimistic because the world is in a really crappy place right now. And my early jobs were working in retail. And so we used to always talk about like faking it until you made it. And so I think there's a certain amount of that disabled people get used to doing, to me, I look forward to a day where as people with disabilities, we're not forced to tell the worst case scenario about our existence to get access to resources that are scraps. And then being told to be thankful for crumbs. I look forward to us not having to sit there and relay the worst poverty statistics when talking to civil rights organizations about how their policy is bad, unless it includes us or to sit there and have to talk about police violence and highlighting the fact that over 50% of the individuals killed by law enforcement are people of color with disabilities to fight for us to be at the table, to be included in those conversations.

Rebecca Cokley:

I look forward to the day that disability is truly that the people doing DEI, or DEIB or JEDI, or whatever they call it this week, actually understand that they cannot use the word inclusion without including people with disabilities, or they're a hypocrite because the word comes from our community was co-opted by the broader diversity space. And so I think that there's, a lot that we can continue to do. And I continue

to feel faith every time my phone rings. And it's another foundation saying, "Hey, we want to do what you're doing." Or it's a individual who has suddenly gotten access to a significant trust fund. And they're like, "Hey, I want to grant make to disability what do I need to know?" and as long as that continues happening, as long as we continue to see disabled people pushing back every time we're not at the table, I think we can still have hope.

Michael Morris:

Ask you one last question. And, again, because of the role you are at Ford, you're not only influencing internally, what's going on at Ford, as you just mentioned, you're influencing what other philanthropic organizations, foundations, corporations are doing. One of, I think the real challenges is that private philanthropic community is over here and government is over there. And do you see opportunities in the future where the two could work together, perhaps seeding, as you said, innovation, really bringing about impactful change that impacts youth and adults with disabilities that improves employment and financial health and economic security.

Rebecca Cokley:

I have a lot of thoughts on this is something I think about a lot. And also Michael, I'm a politics addict. I love politics. I love campaigns. I just finished. I just wrapped up the most important campaign I've ever worked on. My son's fifth grade student council election is, was today at, 11. O'clock still waiting for results. I think that there is the opportunity for increased conversation. I think as we're seeing folks on the hill actively talk about asset limits, as they're talking about paid family medical leave. And we know that people with disability 40% of people with disability have access paid, leave to care for someone who's not a biological relative. Like these are PLA tables that we need to be at. And as boards pushing, and we're seeing a number of our colleagues in the philanthropic space push for an increased understanding of what inclusive economic justice looks like.

Rebecca Cokley:

And we're seeing the Hills start to have these conversations. We can't have them in a silo. We have to sit down with each other so that they can ask us, what are you seeing from your grantees? Like, what are you

seeing in the field? We can reach out to them and say, Hey, we're missing something happening in your district. Like, we've heard that there's this innovative thing, or what is it that you're thinking about? And obviously being very mindful of C3 rules and not lobbying, but how can we educate and inform each other on best practice so that it no longer is the right hand, not knowing what the left hand is doing, but us working in conjunction to drive the kind of change that disabled people expect us to be driving?

Michael Morris:

Well, Rebecca, as always your vision, your views, your perspective are, absolutely what the world needs to hear. Hopefully this podcast will be listened to by thousands of people across the country, employers, policy makers, people with disabilities and others. Thank you so much for the time today. And we just appreciate you and what, you're doing. Thank you.

Rebecca Cokley:

Thank you so much, Michael. It's always fun to be here.

Voice Over:

You've been listening to let's get to work. Reimagining disability, inclusive employment policy brought to you by the Burton Glad Institute at Syracuse university. Don't forget to subscribe to the podcast, Apple podcast, Google podcasts, or wherever you listen to podcasts.