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JUSTICE SHORTER:

Welcome back folks to another episode of Disability Inclusion Required. I am your host, Justice Shorter. Today we focus in on healthcare. If passed, newly proposed cuts to Medicare and Medicaid services would have disastrous impacts on people with disabilities nationwide. This episode we're joined by Henry Claypool and Jalyn Radziminski to discuss where we are and how we can collectively shape where this country is going concerning healthcare services. Henry works as an independent consultant applying his knowledge of disability policy primarily in the health and technology sectors. His experience in public service includes advising the Secretary of Health and Human Services during the drafting and implementation of the Affordable Care Act, and advising the administrator of the Centers for Medicare and Medicaid Services on implementing the Supreme Court's Olmstead v. Lois Curtis decision. He has worked on disability issues at the state and local levels, leveraging his lived experiences as a beneficiary of the social security, Medicare and Medicaid programs.

Jalyn is the founder and CEO of Count US IN, the first national and Indiana-based nonpartisan nonprofit led by BIOPOC disability community members that increases and diversifies voter turnout and broader civic engagement. Jalyn is also an elected commissioner and vice chair for Indiana's disability rights protection and advocacy services. At the national level Jalyn is on the board of the American Association of People with Disabilities and previously served as the director of engagement at the Bazelon Center for Mental Health Law. Jalyn's work is informed by their lived experiences as a black and Japanese activist student and young professional with mental and physical disabilities. Jalyn graduated from Emory University and will graduate this May with their JD from Fordham University School of Law. Congratulations in advance, Jalyn. Believe me folks, you don't want to miss this episode. Let's get into it. Henry, Jalyn, thank you both so much for being here.

HENRY CLAYPOOL:

Hello. It's a pleasure to join you.

JALYN RADZIMINSKI:

Thank you so much. Very honored to share this space with you both.

JUSTICE SHORTER:

I'm so happy to have you. So we're talking about healthcare today and I wanted to begin by asking both of you about a moment in your life when you felt the most cared for. How did it shape you and your understanding of care systems in this country? Jalyn, let's start with you.

JALYN RADZIMINSKI:

Sure. So as a lot of y'all know, I work and I'm also a law student, so access to education and the intersection of healthcare has been at the top of mind for me as I'm applying for accommodations to take the bar exam. So when I think of this question, something that popped into my mind immediately was when I first accessed accommodations in college. So in addition to just different mental health and physical disabilities, I had to undergo a lot of surgeries in college where it changed my mobility in a way that I never experienced prior to that. A lot of wheelchairs and crutches, that compounded some things.

And there is just this week where, just when I was back on crutches for the first time, able to move around, I was trying to get to ... Basically I was in a wind ensemble. I played the baritone and I really wanted to get up there to go to practice because playing music really helps me feel better and just express myself. And I remember it was the first time I was on crutches after the surgeries. And I was in Georgia, Atlanta, Georgia so it was very hilly compared to the Midwest where I'm from and I was, using my crutches going up this hill and it started raining on me and I was just sobbing because it was just so hard to get there. And all of a sudden the rain around me just stopped and I was like, "What is this?" And I look up and it's another student holding an umbrella. I didn't know the student. I didn't know her at all. She's like, "Hey, I just saw you and I just want to help and I'm going to walk with you up this hill." And that was so meaningful for me because it really made me reflect that healthcare isn't just a hospital building. A lot of times it is community showing up for each other. And that really just meant a lot to me.

And the remainder of that week I was navigating different medications for the pain of surgery and how that impacted my classes and accommodations and just having nice peers around me like that while also having just a student success program with social workers that helped me apply for additional accommodations, navigate classes and transportation so I wouldn't spend a fortune on Ubers. Just navigate that with doctor's appointment. It really meant the world to me and it was community members that I knew. It just felt like a full wraparound system of care. And honestly experiences like that, I not only felt cared for health-wise, but I felt cared for and seen as a whole person and that's really just shaped why just in the work, just at the professional leadership level and just in my personal capacity I really advocate for community-based systems and just peer support and coalitions that just can show up for each other because that's what really made me feel cared for and support as a person and it made me feel like I wasn't a burden to anyone that's. So that's just a memory to me. That week really always stuck out to me. Yeah.

JUSTICE SHORTER:

I love that story because we are all dealing with a lot of uphill battles, what seems like an uphill climb and having an ally beside you to support and assist and to just be a shoulder to lean on is certainly helpful in these times. Henry, I want to come on over to you. What's your response to that question?

HENRY CLAYPOOL:

Let's just have another college story. For me I was a sophomore in college at the University of Colorado skiing and I was injured and I became a member of the disability community. So it was an experience that really has shaped me obviously and informed all of my work since then. But the systems that came into place were really significant. Played a very significant role. I became eligible for the social security program and the SSDI and SSI programs. I became eligible for

Medicaid and eventually Medicare. And later I received a Section 8 housing voucher from HUD to help pay rent so I could go back to college. I had vocational rehabilitation to help pay for the costs of continuing in college. And programs like SNAP ... It's a food assistance program because I had such modest income from SSI I was eligible for it. Helped with bringing those resources in.

In Colorado it can be cold and there's a program that helped pays for energy assistance and I became eligible for all of those programs eventually. And it really allowed me to focus on my studies in a way that I wouldn't have been able to. My family didn't have the resources. In fact, having the family responsible for taking care of my needs would have resulted in our impoverishment and bankruptcy. My father was still paying for student loans and had just recently purchased a home and this was back a while ago and was paying a mortgage rate when interest rates were extraordinarily high. Like 12% interest back in the mid '80s. These programs really did show me that the nation has a heart and when it's at its best it's there for people that need it.

JUSTICE SHORTER:

Henry, I want to stay with you for a second. Can you give us more of a situational snapshot on what is happening with Medicaid and Medicare services today and how it is directly impacting people with disabilities, those very services that were so instrumental when you were younger and up until today?

HENRY CLAYPOOL:

Sure. The Medicaid program can get quite complex and so can the process that the Congress is going through to make cuts to the program. So I think it's best to just keep this simple. And the reality is that the magnitude of the cuts, $880 billion that are called for in the house budget resolution, there's no way that the committees that are responsible for that can actually get to that number without making very significant cuts that will impact disabled people in very significant ways and they could run the gamut. There could be changes in eligibility, making some people ineligible based on how much money they have, the types of services that they receive, where those services are received. One of the things we fear is that it really results in a contraction in community-based services and forces people back into institutions and we have a long history of institutionalization in the country and these Medicaid cuts really threaten the very nature of the program and many of the gains that the disability community has fought for.

JUSTICE SHORTER:

You spoke about community-based living. I'm also wondering if there is anything that you want to share by way of the current situation with the administration for community living and what is happening with that agency right now?

HENRY CLAYPOOL:

Well, you've touched on a real personal issue. I worked for the Secretary of Health and Human Services. During the Obama administration I was the director of the Office on Disability and I worked with the assistant secretary for age and Kathy Greenlee to form the Agency on Community Living, ACL. It's important not only to the people that depend on the nation's programs for older folks and disabled people, but also I would argue to the very agencies that are responsible for running them. And their value I think may be lost on the current administration in both regards.

In terms of what they do for the agencies, they help provide a part of the department that can engage more directly with beneficiaries of these programs to understand and hear and work on the issues that concern them that could be improved and stand to have better coordination with other federal agencies. As you heard from the list of things I told you, I became eligible for, community living really requires a cross-government approach. So that coordination was uniquely taking place at ACL and that was one of the reasons we founded it because older adults and disabled people really rely on that level of coordination.

JUSTICE SHORTER:

And you all being a part of the founding of ACL is certainly one of those disability victories. We're going to come back around to that a little bit later. But now I want to go ahead and bring Jalyn into the conversation. Jalyn, how will reductions in social security staff and requirements to show up in person for certain services disadvantage people with disabilities? How does this further strain a system that is already infamous for service delays and denials?

JALYN RADZIMINSKI:

Definitely. And it's also just such an honor to be in conversation with Henry as one of the founders of that. I'll say the office is shutting down and people being fired from the Social Security Agency will really exasperate wait times and inaccessibility to really access what I'd call essential social safety net resources. I stay away from public welfare programs. I always call them social safety net resources. But people's access to benefits, healthcare insurance and things like food stamps and so much more. And like Henry shared, this is all under just a broader challenging backdrop in addition to ACL being reorganized, the Office of Civil Rights and the substance abuse and Mental Health Service agency or SAMHSA is also being consolidated. And I know just from my lived experience growing up on food stamps and later in life, really relying on programs related to mental health that are funded by SAMHSA have been really critical for me to be able to stay in the community.

And with offices in addition to the Social Security office shutting down, it's really going to continue to devastate our community and exasperate these issues at just all the different intersections of holistic care for our disability community and those who are aging. And with the social security staff really being reduced, it really especially harms the disabled community members in rural areas. Just from my experience organizing in rural Indiana, a lot is done in person and for some agencies to potentially leave some of these areas, it's really critical to be able to go to these types of venues in person, but also the requirement to go in person is also harmful for those who have disabilities that cannot transport themselves. And I'll say this will compound what's already challenging in some rural areas like in my home state where there isn't a big transportation structure, let alone an accessible transportation structure to get to any agency that may still be open as they're continuing to close them down, a lot of folks in rural areas also don't have access to internet or online systems. So moving on to that type of model is also challenging.

So besides going in person to access social security staff and ask questions, people usually use the phone, but with staff cuts it's going to be harder to connect with staff as well with long wait times. And it's also just going to exacerbate times where people are waiting for their disability benefit claims that a lot of our community just urgently relies on in general to get those monthly payments for those of us who aren't able to work at the time or have limited ability to work at the moment. These are the types of just essential day-to-day life programs that people rely on from social security and these cuts will exacerbate the issues in these ways and it's going to be compounded by just the shutdown and reorganization of a lot of other critical agencies in this holistic system that Henry outlined. And unfortunately, it's all being done under the guise of what some say efficiency, but I say it's not. It's just going to cause more strain and accessibility for the communities that these agencies were created to serve.

JUSTICE SHORTER:

Absolutely. Directly impacts someone's ability to make a decision for themselves on whether or not they show up in person. Imposing this requirement that folks show up irrespective of whether or not they have the means to do so. Very similar to what we're seeing around requirements and rollbacks of remote work options and telehealth services as well. I want to also ask you to expand a little bit on why so many folks right now are concerned about increased surveillance and scrutiny. How do such practices from the government impede on somebody's ability to receive equitable health care access?

JALYN RADZIMINSKI:

Definitely. And just as a point too, just as a law student, there's so many different concerns about increased surveillance by the government now and the risks that poses. And just for the future of our career and livelihood and in some cases even being able to stay in this country. So when we add the layer of what that does to health care, there's a huge concern right now, especially in relation to social security information because right now there's been a lot of attempts by some government agencies to really access our data from social security, which contains a lot of sensitive information like where we live, our medical history, our banking information, our tax information, our citizenship status, our family records and benefit amounts. And a lot of those things are already very sensitive information, but just living in this climate, there's just ... For instance, our trans and non-binary disability community members have a lot of concerns of policing of our bodies and how we express our gender.

A lot of us in our disability community that intersect with immigration status or have green cards are very concerned with people who we do not want to have access to that information, access to that information on top of just our health care information being private. And the over concern and search for fraud that's driving a lot of these efforts to access our sensitive information is really going to not only cause harm to our communities and our privacy, but also just really create more disillusionment and reluctance to access these systems. And like we've been explaining a framework that is just rapidly crumbling. And what's a bit more concerning is recently the Commerce Secretary even pitched paused social security checks to vet our information for fraud. Luckily federal courts have paused these type of efforts to access our information, but there's still a lot of concern right now. Not only just for our information being in hands that we do not trust or that should not have that information in the first place, but also just creating distrust in the healthcare systems that we urgently also depend on to provide funding to get access to healthcare. And honestly, a lot of this has led to lot of us in organizing and advocacy spaces to really emphasize digital security culture just wherever we can. But with things like this, it's very hard to have control over that as an individual.

JUSTICE SHORTER:

This is why we need to think about collective organizing and mobilizing. Absolutely. We'll talk about that a little bit more later as well. Henry, many folks in the disability community, you being one among them have been here before with respect to fighting for healthcare rights. And I will say this, many, far too many are no longer with us. Can you guide us through a brief timeline of disabled healthcare victories though? Why is it important for donors to be aware of this history when making funding decisions today in the present?

HENRY CLAYPOOL:

Sure, and I think it mirrors some of the civil rights protections and brings in a disability context. So in 1973 there was a rehabilitation act passed and section 504 of the Rehabilitation Act contained a non-discrimination clause. And so section 504 requires recipients of federal dollars basically not to discriminate against disabled people. And so that was a framework that was fought for and hard won. We finally had implementation of it later in the '70s and throughout the '80s I think the community was really focused on a broader set of civil rights moving beyond just these federal funded entities and wanted to make sure that we could have these broader rights like those for employment protections and rights to communication. And that led to the passage of the Americans with Disabilities Act in 1990. And that, of course was a high watermark for our community and really welcomed us into the civil rights community with significant status.

In healthcare it progressed on. In 1999, the Supreme Court heard a case called Olmstead and it was about the right to live in the community when one is receiving Medicaid funds. And if people are going to be receiving these long-term services and supports, they need to be getting those in the most integrated setting appropriate to their need. And states have an obligation to do that. And the Supreme Court found that in this case .and I happened to be working at the agency when that decision was handed down and we have worked on guidance for states and that really kicked off a great deal of work around rebalancing the Medicaid program, moving people out of institutions and into the community. And thankfully that work continues today. We still have Olmstead protections. We're wary of this Supreme Court and what it might do to those protections. But as long as we can avoid a case going up and being heard by them, it's still the law of the land.

That rebalancing work was one of the things that really led to the need for an agency in HHS because to rebalance Medicaid, you not only needed access to Medicaid, but of course you needed housing. Once you're in the community, we have to be thinking about your transportation needs so that you can get to and from. And ACL, that was our original vision for the agency was to really serve not only as an organization that was in touch with the advocates, but also working within the federal government to have better coordination to ensure that the direct care workforce is getting its wages paid appropriately. We have a direct care workforce shortage and we've had some significant investments in the last administration that allowed us to raise wages and thankfully we are addressing some of those issues.

Let's hope that we can continue to hold onto those gains and pay our community-based workforce a wage that will sustain them so they can deliver the quality of service that people need. Those are a few of our victories, and I think it's important that donors be aware of this just because the federal government frankly wasn't doing the coordination and ACL, the Administration for Community Living, it still exists, is very small and it really requires others on the outside to be more active, especially funders in supporting these activities and helping states learn more about how to support people in the community. How groups of disabled people can come together and make sure that they have appropriate representation and that they can bring their lived experience to policymakers to really inform the policy going forward. In my personal experience, that was really what I've drawn on. And so I've been privileged to have this position and do this work, and now we need to make sure that other people have the same level of support to make sure that their perspectives are heard and policymakers understand their needs. I happen to be white. I have a lot of privilege. And marginalized communities aren't well represented in these policy discussions and funders can pay particular attention to making sure that those voices and that we have leaders coming from those communities as well.

JUSTICE SHORTER:

Indeed, indeed. And Henry, in the beginning of this conversation, you shared a bit about your very real fears around your family being exposed to additional debts because of the medical services or treatments that you needed years ago. And Jalyn, can you speak to how cuts to Medicaid would increase medical debts and potentially thrust millions of families into bankruptcy? How would disabled folks be impacted in general and what is at risk for those in rural and low resource communities in particular?

JALYN RADZIMINSKI:

Speaking of donors, I think Henry laid it out so well too that it's just so critical to invest in groups advocating to protect Medicaid at the national and local level, as well as holding the line to stop harmful cases that could potentially chip away more at these fundamental disability rights that so many communities rely on. And when it comes to cuts to Medicaid, it's so concerning because Medicaid is the largest program that helps intersectional families, but especially families with low income to be able to have access to healthcare. And it especially helps those who are most near the line of poverty and low income. And medical bills are the leading causes of debt, especially in this country. And reducing access to Medicaid can really just cause our access to this support and could put millions of people in severe medical debt that could lead to bankruptcy. Medicaid, it helps almost 80 million people cover their health insurance and supports those key programs like home and community-based services to stay in the community and not in institutions.

And just to add more of an intersectional lens to that, out of the 80 million people, 20% of us who use Medicaid are black, 27% are Latino or Hispanic, 5% are Asian. And I'll say just everyday people and just across generations this could cause bankruptcy and financial struggle. I'll say in this backdrop, I'm doing a lot of organizing to stop cuts to Medicaid, but at the same time, I'm the third generation of a black and Japanese family and I'm balancing school loans, I'm balancing my healthcare and at the same time I'm supporting my mother who's taking care of my grandmother who was diagnosed with cancer and has a language barrier and partially deaf. And for us to make sure she could stay in the community. I worked a lot with my mother to support her. And I don't think a lot of people also think about, Medicaid I'm a direct beneficiary of state health insurance, but so is my mother because caretakers also are supported by Medicaid to help us stay in the community together. So cuts to this can not only cause financial disruption to us individually, I just wanted to share that because it could potentially disrupt entire generational family structures that are committed to supporting each other and thriving and succeeding while accessing healthcare and staying in the community.

In rural communities specifically, I guess I'll probably identify more as a suburbs person, but for rural communities that I have friends with and work in, I've held community engagement sessions over the past five years and cuts to Medicaid will completely ... I feel like I keep saying exasperate, but it truly will exasperate the challenges that already exist. There's already a struggle to access healthcare in a lot of the rural communities that I serve. And Medicaid is so essential, especially for rural hospitals to continue running and for people in rural communities to have their insurance covered, to access the hospitals. But on top of that, it's going to be compounded because in a lot of communities I serve, there's already a shortage of therapists, counselors and social workers that can provide the services to keep people in communities and further cutting access to Medicaid will only devastate these communities more and make it harder in the backdrop of these conditions. Yeah.

And honestly, I'll just wrap to say reducing Medicaid is just the opposite of what our community has asked for over the years. This isn't the first time that Medicaid is threatened to be cut in funding. On top of the funding cuts, there's been a lot of advocacy to stop adding work requirements, asset limits. So because a lot of people really depend on this for healthcare and like I said, to stay in the community, it's just so essential right now for us to work at the national and local level to keep Medicaid going and to keep it funded without more administrative barriers because I'll say at the local level too, in Indiana, we just had to advocate to not put lifetime limits on our access to state Medicaid, which would have said, "Oh, after three years, good luck, buddy. No healthcare for you anymore if you depend on us." And that would be devastating. And it's just so unrealistic for those of us in the disability community and just other chronic things people navigate like my grandmother with cancer. So it just adds financial burdens. And just beyond that, I just can't emphasize enough how it can completely disrupt the way that we would be able to navigate in society.

JUSTICE SHORTER:

You talked about your organizing experience and how you have been intensively working with communities over the last several years on these issues. Henry, I want to bring you back in here. What can funders do to better support disability organizers who are pushing back on budget decisions like Jalyn just described, especially the decisions such as Medicaid cuts, these cuts that are severe and unfair, and might I add, which would also be deadly and dangerous if instituted?

HENRY CLAYPOOL:

Yeah. This is challenging because the talking points on the other side that want the cuts are not always accurate. And so saying things like we only want to introduce work requirements for the able-bodied when in fact Medicaid really covers lots of disabled people through all the different eligibility groups. And so our advocacy organizations need to have better access to better resources so they understand these details and that they can have good communication strategy for pushing back on these talking points. So for example, with work requirements for able-bodied folk, well, the reality is that disability in the Medicaid sense has a really stringent eligibility criteria. And in fact, many people in a eligibility group called the expansion, which is one that the talking points will invoke are said to be able-bodied.

Well guess what? Many disabled people live there and rely on Medicaid for that coverage. They may just happen to have diabetes or some other disability. And that doesn't rise to the level of needing the kinds of long-term services and supports available through the Medicaid program. So it's important to be able to engage in the debate but not allow your message to get lost on the technical complexities of the program, but push back in a straightforward way that hold policymakers accountable for cutting the services of the people that they represent. And in fact, there are a number of house districts where representatives have voted for this budget resolution that represent an extraordinary number of people with Medicaid. A lot of rural folks and rates of disabilities in states like Kentucky or West Virginia are very high where there were a high percentage of Trump supporters. So this is something that we need to be able to draw attention to and make sure that the policy makers don't get away with using disingenuous or inaccurate statements about the characterizing the Medicaid population in certain ways.

The cuts are going to hurt disabled people regardless. We really need to push back and the community has done a good job. But to be able to sustain this through the process that we're going to go through, I think funders really need to pay attention to those groups that are on the front line and find ways to get them the resources that keeps them in the fight.

JUSTICE SHORTER:

Absolutely. Absolutely. In black culture, it is often said that we don't want to lose no recipes. A sentiment that is shared in recognition of lessons passed down over generations that nourish, protect and heal the body, mind, and soul. Can both of you close us out by sharing what recipes, IE lessons about equitable healthcare that you hope will help guide future generations of disabled leaders as some ready themselves for the very first time to join in on efforts to save Medicare and Medicaid services? Jalyn, I want to start with you.

JALYN RADZIMINSKI:

Yeah. So thank you so much for that question Justice. Something that I've really reflected on over and over just every time that I feel stressed or tired or overwhelmed is I reflect a lot on Lois Curtis. Earlier we mentioned the Olmstead case. The full name of that case is Olmstead v. LC. I always love to emphasize that LC is Lois Curtis, a black woman with intellectual and mental health disabilities. And she's now my ancestor that I really hold closely because to me, it represents and shows in times like now, yes, we have so much precedent set. We all worked so hard to advocate for these issues, but she also shows to me that how important it is continue to resist institutions, to resist oppressions that are compounded by race and disability. She also just to me represents that all of us, even in the forefront of the fight, we're still vulnerable. As a law student, I'm advocating to really work towards liberation for black and disability communities through a disability justice lens. But then I think about her, where even after that victory, she still had to fight for her own rights to get back out of institutions despite creating that right for herself and this entire country.

So I think about her because just for us, and a lot of folks in my generation, we're really wearing ourselves down at a rapid rate, and for me, I like to just remember people like her and read a lot just from different critical race scholars to really center myself to understand and heal that I'm going to keep doing this fight. But I also have to remember that as someone who is also directly impacted, I also have to center disability justice principles to really ensure that I'm okay and can sustain myself because if we're not here, who's going to continue to fight for the long haul. So I really center stories like hers. I really read a lot of disability justice and critical race literature to just meditate and really center healing and center myself in the midst of so many battles happening at once. So for me, the recipe is I try to do my best as a younger leader still finding my footing in this space to keep stepping and pushing forward, but also just allowing myself and pausing in that internal ableism to pause and ask more people for support.

JUSTICE SHORTER:

You mentioned reading, and I am a bibliophile. I am constantly reading, so you and I are going to have to throw some book titles back and forth at some point very soon. I'm also so thrilled that you mentioned Lois Curtis. I created a series several years ago called Disability Rights in Black, and she contributed a video message, which was incredibly short. She just said, "Happy Black History Month, and I'm glad to be free." And to this day, it gets me going. It gets me pumped. It buoys my spirit. Henry, I'm coming over to you. What's your recipe, sir?

HENRY CLAYPOOL:

Yeah. I would have to echo Jalyn's sentiments there that really get in touch and know the history of our movement. And it can be a place of support and sustain us because there will be a time we're on the other end of this struggle and there will be opportunities in the future again. And remembering from our history where we've had success and how we've fought and the strategies we've employed, I think will be really beneficial. Another piece is always get in community and find support for yourself so you can be sustained in these times. Because right now it's hard and we're all experiencing a great deal of loss and bewilderment. And community is one place to go, to be fortified and to care for one another and know that together we can get through this. And on the other end, hopefully we'll all be there together to continue our journey. But I think those are just a few of the sentiments I'd want to share.

JUSTICE SHORTER:

I needed both of you today. I needed your words, I needed all of your energy, your wisdom, your care. We appreciate you all so much. Thank you for joining the podcast today.

HENRY CLAYPOOL:

Thank you.

JALYN RADZIMINSKI:

Thank you.

JUSTICE SHORTER:

If you want to keep your learning journey going, visit the Disability and Philanthropy forum at disabilityphilanthropy.org. I'm Justice Shorter, and this has been another episode of Disability Inclusion Required. Thanks so much for tuning in and join us again next time.