Disability Visibility Podcast

Episode 9: Medicaid and Community Living

Guests: Dominick Evans and Andraéa LaVant

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[atmospheric music]

DOMINICK EVANS: Without community living, what do we have?

People don't see me as a human being. They don't see me as deserving services.

ANDRAÉA LAVANT: We, as American citizens, are supposed to be able to work hard and get a good education, all of this stuff to build a life that we want, or that we do deserve. It's something that's seemingly simple, right?

[hip hop]

LATEEF: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE WONG: Heyyyyy! My name is Alice Wong and I'm host of the disability visibility podcast, conversations on disability politics, culture, and media.

Medicaid is the primary payer of what's known as home and community-based services. For me, these services allow me to have people help me get out of bed, take a shower, almost everything.

Freedom means something different for disabled people on Medicaid, at least, that's my perspective. There are disabled people all over the United States that have to live in institutions because of their needs and the lack of services in the community. Plus, many folks still don't imagine or expect severely disabled people to be able to have families, careers, or their own homes.

Today I'm talking with Dominick Evans and Andraéa LaVant about Medicaid and community living. Community living is the concept that disabled people, despite their level of care needs, have the right to live in the community with adequate support services they can direct on their own.

Being on Medicaid isn't a choice for people like Dominick, Andraéa, and me. All three of us rely on Medicaid-funded personal attendant care for our everyday activities. It can be a soul-crushing grind.

Andraéa lives in Maryland and Dominick lives in Ohio. While each state administers Medicaid differently, they both fought to get the services they needed and expended significant labor to remain eligible and frankly, alive.

[atmospheric music]

One thing to note: in this episode, we discuss how Medicaid is a poverty trap. Medicaid’s rules on assets and income are strict--you have to live near poverty to participate in the program. This keep disabled people from pursuing their life goals just because they need personal assistance. So, what does it mean when your well-being and freedom is tied to a single program? Why do disabled people have to make trade-offs on how they want to live in exchange for mere survival?

Let’s hear from Dominick first. [electronic beeping] Are you ready?

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

ALICE: Away we go!

Dominick Evans Interview

DOMINICK: I'm a filmmaker, and I spend much of my time working as an activist through my creative work as well as through the work I do for the Center for Disability Rights as a media and entertainment advocate and my own personal activism as well.

ALICE: You used to live in another state, and then you moved back to Ohio. It is really hard to reapply for services that you need because they vary from state to state.

DOMINICK: It really has been a struggle. Around 2014, I got a job opportunity in New York. When we moved to New York, it wasn't until I appealed the decision that they decided to give me the hours I needed.

My son is also disabled. They kept telling him he wasn't eligible for Medicaid services even though he was on Medicaid. We moved back to Ohio because there were better services here for him. For me, it's been a real struggle. I moved back to Ohio in October, and services are still not right.

I depend on home care for dressing, bathing, going to the bathroom, getting into my wheelchair, eating and cooking and cleaning.

I strongly suspect that because I'm transgender, that was the reason they did not wanna approve me because my paperwork was littered with horrible, horrible assessments about me being not a man. I'm legally male, but the assessment was about how I'm a person dressing up as a man. You think it would be pertinent to mention that I've had spinal fusion, that I've had problems with my stomach, things like that, that intersect with my disability. But what they did mention on the paperwork was that I had sex change operations.

I feel like we constantly have to explain everything about our lives and why we need services and why we benefit from services. And it's exhausting. I even had a hearing in which I had to sit and listen to a guy defend why I don't deserve home care. Part of it is because I live with a "roommate" who should be forced to do all my care, ignoring the fact that anybody I live with, they can't have another job. So, the state wants them to work for free to do a full-time job of care for me and not have the ability to work. We would never be able to afford our rent or food.

It's not at all lawful, here in Ohio, to request your roommate to do this without getting paid.

I went to the program Buckeye. I was able to get someone out to evaluate me, and she said I needed as many hours as I needed before. They have a record. I was on Buckeye before. They know what I need. They gave me home care, but they're now saying I deserve half the amount of hours.

When you lose access to home care, you end up in a nursing home

ALICE: You and I and Andraéa all have progressive disabilities. So, our needs are always gonna be growing, if not staying the same. It's very arbitrary and outright discrimination.

DOMINICK: Yeah, exactly. Right now, with my current hours, I can go to the bathroom once a day. Once a day. I can eat one meal. They think that I can just have a snack.

Without this access, I'm gonna end up in a nursing home. My best friend, my sister--I don't have family, but this is my sister--she's trapped in a nursing home because something happened where she had to leave her home. And she's been fighting for two years to get out of a nursing home. She's neglected in the nursing home. She'll message me sometimes on Facebook at 1:00 am telling me to call the nursing home because her call light will not come on, and she needs help. They're taking 90% of her income for the nursing home. That's what they do. If you get Social Security or SSDI, they take 90% of it. So, getting her into an apartment is not that easy when you need a security deposit, things like that.

The Olmstead Ruling says that if she is eligible for care and can live in her own community, which she did fine prior to getting trapped in a situation she couldn't help, it says she should be able to have that care. We filed an Olmstead report for her, and she got an email saying, "We don't have the resources to help you."

That reality could become mine very quickly.

Nursing homes versus community living: ableism, queerphobia, racism, and transphobia

ALICE: Especially this past year, we've all been acutely aware that we're all one step away from incarceration in a nursing home. And a lot of people without disabilities think nursing homes are great because there will always be somebody there 24/7. So many non-disabled people don't even realize what community living could do and what it offers.

DOMINICK: Community living allows me to have a job. It allows me to live with people I care about. Essentially, I feel like we go to nursing homes to die.

ALICE: You're in an institution. You basically give up any sense of privacy, any sense of decision-making. Older adults also, they can live, with the right supports, in the community. It's not just about younger disabled people in nursing homes. But I think one of the underlying things that we've been talking about is really about ableism and how it shows up in policies and programs.

DOMINICK: Ableism certainly plays a role in all of this. When you're multiply-marginalized, your identities kind of compound on one another. Like for me, I think transphobia and queerphobia are also playing a role. Being a transgender disabled person has had a much more devastating effect on my ability to have care and also knowing that I'm safe, you know? So many people have told me, "You're a freeloader. You're lazy. We shouldn't have to pay for you." Some people have even suggested that people like us should be euthanized.

[somber atmospheric music]

And also, just witnessing the way race and racism plays in. My friend, G, is a Black woman, and we've had a lot of discussions--not just her, but me with other disabled people of color--we've talked about how white people are different about elder Americans or their grandparents. And we see cultures, especially in communities of color, where parents feel it's their obligation to care for their grandparents and their great grandparents. And it's an honor.

G has said her family hasn't been able to afford to not work and to take care of her, and there's a lot of guilt there because families are expected to. As a white person, I don't think that there's always that loyalty.

[upbeat music]

A magic wand to transform Medicaid's community-based services

ALICE: So, Dominick, if you had a magic wand, and you transformed Medicaid's community-based services, not just in Ohio but everywhere, what would it look like?

DOMINICK: I think that it would be a streamlined system that was federal so that we could move between states. PCAs would get paid above a living wage. A lot of the home care workers are women of color, overwhelmingly, and they deserve a living wage. Also, the cost of our care, we're talking at least $100,000 per year, per person to put us in a nursing home. So, for most of us, our care is equal or less than that. For me, it's less than that. So, it's cheaper to keep us in home.

So, unless we're making $250,000 or more, I don't think that they should be looking at our income, specifically for home care. It not only limits our ability to have care and to work, it limits our ability to get married because our spouse's income is included. For some states, it's like if you make $28,000 and you're a family, you can't get home care. We need to be able to have jobs and not have our home care affected. And also, it seems redundant for you and I to go through evaluations every single year. My SMA's not going away. Is yours?

ALICE: Not anytime soon!

DOMINICK: And it's just a waste of taxpayer money. It's a waste of time.

ALICE: I would love it if non-disabled people would just really get a sense of would you put up with this? Fuck no! So why would you tolerate this for anybody else?

DOMINICK: This is life or death for me, and I don't think a lot of people connect that. I think they just think we're a bunch of angry, yelling [chuckles] kind of--

ALICE: Unreasonable, over-dramatic--

DOMINICK: Whiny--

ALICE: self-pitying people that are so self-involved.

DOMINICK: If you give me the things I need, I would just live my life, 'cause that's what I want. I just wanna live my life.

ALICE: Everybody deserves to have choices. Right now, for us, choice is a privilege.

Wrap-up

ALICE: So, Dominick, how can people find you if they wanna check out what you do?

DOMINICK: My Twitter handle is @DominickEvans. Or you can look through my website, DominickEvans.com.

ALICE: Thank you so much for joining me today, Dominick. I appreciate it.

DOMINICK: Thank you. Thank you for having me.

[chill music]

Andraéa LaVant Interview

ALICE: Now, my conversation with Andraéa.

ANDRAÉA: I currently live in the state of Maryland. I work in Washington, D.C. I've always worked in the non-profit arena for both national and local non-profits in youth development and leadership, specifically focusing on young people with disabilities.

ALICE: So, tell me, what does Medicaid mean to you and to your life?

ANDRAÉA: Medicaid really is livelihood that allows me to remain just who I feel that I am. The services that I use, personal care attendant services, is literally somebody coming and getting me out of bed every day, prepping me for work, helping me with all the Activities of Daily Living: Bathing, dressing, grooming.

You know, when I turned 18, I became a recipient of SSI, Supplemental Security Income. I had that through college and then for a year while I served as an AmeriCorps member. So, I was in the state of Tennessee. After college, in Tennessee, the Medicaid services came in. When I moved to the state of Maryland, I went to the Social Security office, let them know I'm working now, and I still need personal care services.

It took two years to actually have assistants. I literally had friends helping me for a couple of years, and I still was paying out of pocket for a while.

Something that I consider a lot here, living in this area is that I pay a lot more for housing because it needs to be accessible, and it needs to be near public transportation. That with that, that adds expense as well.

[mellow guitar music]

Crowdfunding to make up for loss in services

ALICE: Earlier this year, you actually had to launch a crowdfunding campaign to make up for the loss in services.

ANDRAÉA: About the second week of June, I received a call from the agency that my caregivers come from basically saying that I was showing up in the system as ineligible for services. I have a case manager of sorts that's a support planner. She said, "Oh, this is interesting, 'cause I just looked on the 1st of June, and you were showing up as eligible. But it looks like they've backdated you." I got a letter a little later basically saying that, "You're not a recipient of SSI, and your income doesn't qualify you for Medicaid." Which made no sense to me because my income has not vastly changed, nor have I been a recipient of SSI in the state of Maryland.

So, I was sharing the story with some coworkers as well. And they were like, Andraéa, we really would love to help. Please start a crowdfunding campaign. It was one of the most difficult things I've ever had to do because I have to put myself completely out there. Looking back on it, I'm grateful that I did it, but it was certainly hard to say, "I need help!"

Oh, my goodness. The biggest headaches, quite frankly, the biggest headaches: Trying to get answers, and brought in the Senator's office, Senator Van Hollen, Chris Van Hollen. It just has been...it's a mess.

Basically, the Senator's office was able to get an appeal hearing set up for me. Technically, when you get an appeal, the services are supposed to start back while you wait for a judgement; however, [chuckles] I'm still paying out of pocket because the systems are just such that I'm still showing as “pending.” And so, it won't allow anybody to serve me.

I don't have a formal lawyer, but I've certainly had access to both national and local organizations that have helped me. So, I have a lot greater understanding.

ALICE: The mistake is on their part, but it's like the burden of proving your innocence is on you.

ANDRAÉA: Yeah. It takes so much. It takes a lot out of you.

Appeals hearing, all the mistakes they made in her eligibility

ANDRAÉA: Literally the day before the appeal hearing, I received a call from the appeals representative, and he verified a few things and then sent me his summary, in essence, the evidence that they will use to prove that I am not eligible for Medicaid. They're saying that I'm not eligible for Medicaid because I don't make under the poverty line. I've never in the state of Maryland made under the poverty line. They also, for whatever reason, had included my income as they coded saying that my income was food stamps. Never, ever in my entire life have I received food stamps.

What I did is I basically shared with the judge and the appeals representative, this is what I know that I'm eligible for Medicaid. Both of them were equally as surprised, like they had never heard. And I thought it was very interesting for the appeals representative, who works for [chuckles] Medicaid, to seem to be very surprised.

The thing is, it's very obvious that they were wrong. So, I'm hanging in the balance every day and continuing to pay for services until I find out.

ALICE: Well, it is great that there was a pretty strong response by the disability community. For transparency, I am somebody who donated to your campaign.

We see a lot of crowdfunding going on for all kinds of needs. We're still completely unsupported by our country, our government. And this is really a huge human rights issue, I think, where we live in such a "wealthy" country, and we still can't get it together to allow disabled people to really be fully integrated and fully participatory in our society. How does that make you feel in terms of, I guess, the reaction and the support you got from your campaign, but also realizing that there's so many other people in your same situation that may not have a campaign, may not be connected to the community, may not use social media and have access to all these resources.

ANDRAÉA: Right, right. And thank you so much. I'm so grateful.

It hurts. It really, really hurts when I see where people are saying, "I'm in my 20s, and I'm already considering nursing homes because my parents are not able to assist me anymore."

I have family; I have a sibling who is younger than I am, but she's built a life down South. When I consider having to drop everything that I've worked hard for to move down to Florida, and I'm grateful for my family, but that's the life that they chose, you know?

I was able to raise quite a bit of money in a very short amount of time, but it stayed at that point. I still only have about three months' worth. I don't have much time left.

[sweeping violins]

A magic wand to transform Medicaid's community-based services

ALICE: If you could have a magic wand and redesign Maryland's services, and how they administer Medicaid and community-based services, what would the ideal program look like in terms of how they treat disabled people and poor people?

ANDRAÉA: The biggest thing is the concept of consumer-directed services. I think it's thrown around like that actually happens, you know [laughs]? If it was really implemented, then I think that would help so much where the person with a disability really is the one that's making the decisions. And obviously, the income, I know very few people that have an extra $30,000 or more sitting around.

ALICE: So, you and I are both, our lives are tied to this program because of our needs for assistance. Being tied to Medicaid has completely reshaped our decisions and our choices.

ANDRAÉA: Mmhmm. Even if I wanted to move to literally a mile or two down the road to D.C. or over to Virginia, oh my goodness! I was thinking about the headache of applying for services again in a different state.

You know, what if I wanna own property or wanna own a rental property and things like that are counted. Even your retirement, preparing for your future. All of those things: Stocks, bonds, anything that you have is counted.

ALICE: And I think that's part of the labor that most people really have no idea about in terms of just the thinking through of everything.

It's really sad when we have our non-disabled friends who are like, "Oh! You should go for this! You should go for that!" And they don't realize how hard this shit is, and in a lot of ways, it's like the mixed messages that people give to disabled people, right? Like, we all have worth, that we all--

ANDRAÉA: Mmhmm!

ALICE: If we all tried hard enough, we'd get our place in the sun. But sometimes I think with these asset and income limitations, it's really not true. Because there's no way for us to move beyond if we are still tied to this poverty trap that is Medicaid.

ANDRAÉA: Absolutely. It's just, oh my goodness. It's so disturbing.

Becoming an activist under the current administration

ALICE: This current administration that we're living under, we've seen a blatant attempt to destroy the safety net, starting with the Affordable Care Act and the obvious attacks to undermine Medicaid. You've been very prominent in terms of speaking at various events, going to protests, sharing your story with a lot of different organizations and groups.

ANDRAÉA: It's been interesting because [laughs] I started the conversation months ago, was asked to just speak about Medicaid and why Medicaid matters to me, sharing that story. And then my services were cut!

I'm over here fighting a little more quietly for my own stuff every day and then advocating on a larger scale for Medicaid that, at the current moment, is not active for me. Not only is it important for me, it's important for so many other people.

ALICE: Yeah, we're not saying it's a perfect program. We, of all people, know the problems with Medicaid. The fact that the Republicans wanna decimate it, that is not helping the situation.

ANDRAÉA: Right. Exactly.

ALICE: That will make it worse for millions of people, not just disabled people, but obviously, children, poor people, older people. Of course, there are problems! That doesn't mean destroy it.

ANDRAÉA: Right.

ALICE: Why can't states really get more people with disabilities in part of the system? Have those folks as the ones administering the services.

ANDRAÉA: Yeah.

ALICE: Do you see yourself as an activist?

ANDRAÉA: Ha! I generally am one that doesn't like to ruffle feathers. I like to pretty much be just...supportive. I think that the current situation has made me an activist, and I'm proud to take that on now. This is definitely not something that I would've chosen to do, but sometimes you're put in a position where you have to, and that's where I'm at, you know?

ALICE: Yeah. I think people with disabilities have always been on the margins, always fighting. But yet, I think something is different this year. I mean, I think in this administration, things are really magnified.

ANDRAÉA: You know, there's so many conversations: Education reform, obviously, there's health care, just I mean, equality. And in general, myself as a Black woman with a disability that carry multiple minority status, I don't see it getting any clearer anytime soon. And so, if I'm given opportunity to, or if I have to create a space, to continue to make my voice heard in an effort to effect change, then that's what I will do.

Wrap-up

ALICE: Well, thank you so much, Andraéa. I guess the last question is if anybody wants to hit you up and find you online, how do people do that?

ANDRAÉA: I am found the same way all over social media: AndraeaLaVant, and there's that extra a, a lot of times people miss. It's A-n-d-r-a-e-a L-a-V-a-n-t. But @AndraeaLaVant on Twitter, Instagram, and Facebook. Same for my email: AndraeaLaVant@gmail.com.

ALICE: Thank you, Andraéa!

ANDRAÉA: Thank you so much!

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You can find links about Andraéa, Dominick, and community living on our website as well.

The audio producer for this episode is Cheryl Green. Introduction by Lateef McLeod. Theme music by Wheelchair Sports Camp.

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Thanks for listening, and see ya on the Internets!

♪ They wanna give a girl hell

Well, admit it hit ‘em ♪