Lisa Tschudi: Welcome to Love Doesn't Pay the Bills, where we make visible the often unseen experience of family caregiving. I'm Lisa Chudi, I'm a family caregiver. As we've previously discussed on this show, there is a looming crisis of care needs in this country. In fact, there's already a tremendous shortage of direct care support professionals who provide day to day support for people with IDD, which is one of the reasons there are so many unpaid family caregivers. My guest is the director of family relations for the American Network of Community Options and Resources. Or Ancor. A recent letter she wrote to Senator Marie Sanders and Senator Bill Cassidy, um, caught my attention. In this letter, she outlines the caregiver shortage and proposes policy measures to address it. Elise Aguilar, thank you for joining us.

Elise: Thank you for having me.

Lisa Tschudi: Would you describe this problem we face with respect to the workforce for direct support professionals?

Elise: Absolutely. Um, so, just to be clear, so I come from the perspective of, uh, uh, the Director of Federal Relations at Anchor, and we represent community, um, based providers across the country, um, who are providing services, ah, specifically for individuals with intellectual and developmental disabilities. Um, the majority of these providers are providing Medicaid funded home and community based services. Um, some of our members do provide services in other settings, like intermediate care facilities, but the majority are providing, um, Medicaid funded HCBS or home and Community Based services. And um, the direct support professionals who provide the supports as part of the Medicaid Home and Community Based Services program are really, um, in the midst of a crisis. So there are a lot of reasons for the shortage that our providers are seeing right now. Um, the program has been underfunded for decades, um, quite frankly, um, the Medicaid program is a federal state partnership and um, states are responsible for setting the reimbursement rates, um, that are paid out for these services. In a lot of cases, these reimbursement rates are honestly just set too low to begin with, and then they're sort of forgotten about for years and years. Um, and so we have this problem where, uh, these reimbursement rates have remained relatively stagnant. And these reimbursement rates, of course, determine, uh, what can be paid up for the service. And that includes everything from the cost of providing the, um, administration, the overhead costs, and the bulk of that goes to paying wages for direct support professionals. And because these reimbursement rates are set so low, um, the wages that DSPs or Direct support professionals can earn are also just very low across the country. Um, we can't gauge exactly, um, uh, what the average salary, uh, is for DSPs across every state, because we don't actually have a comprehensive way to collect that data specific to DSPs.

Lisa Tschudi: Oh, wow, that would seem like an important piece of information to gather. I, um, know in my state it's relatively generous and some of the pay levels that I've heard about in other states are even shocking from this perspective. Um, I know it does vary a lot.

Elise: Yeah, it does, and that's a great point, and that's one of the, uh, policy, uh, priorities that Anchor has is creating this, uh, mechanism to gather this data on a comprehensive nationwide, uh, scale, because we simply don't have that right now. We do have data to collect on the direct care workforce, which is a little bit broader than specifically direct support professionals. And we do have mechanisms to gather data on direct support professionals, but it's a voluntary system where states opt in to the survey, um, conducted by National Core Indicators. Um, and I think the most recent is something like 26 or 27 states participate in that. So we can use that data, um, and we can say from those states where the data is collected, the average pay is around 14 ish dollars. And we know $14 an hour is not a livable wage, it might be above minimum wage in some states, um, but it's certainly not enough to support a person. Often DSPs are, ah, predominantly women, women of color supporting families, and that wage just certainly, it just isn't enough. And so we have this system, um, that we've had for years and decades that simply can't support, uh, a workforce over the long term, uh, in a meaningful way with the wages that they're earning. And then into this already, uh, really problematic system, we had the COVID-19 pandemic, and that, of course, just exacerbated where the workforce shortage already was. Um, I think we can look at surveys that have been done across the country, just asking DSPs kind of what's the impact of the COVID-19 pandemic been on you? And, uh, overwhelmingly, DSPs, uh, say they're just experiencing intense burnout. Um, quite frankly, we're being asked to work in conditions, um, that are really challenging already. Um, and then, um, you're in a system where you have to provide those supports many times, right in person, face to face. There were issues with getting PPE, I'm sorry, early on in the pandemic, uh, there's been just the understaffing, meaning that people are working double or extra shifts, or working in conditions where they shouldn't be, because they're down another staff member. And so we have this entire system that's already pretty fragile, with a pandemic coming in and making it even worse. And so now we're in this place where, um, the pandemic is winding down. In fact, uh, the country has said, we're coming out of a pandemic, we are going to end the public health emergency declaration. Um, and with that came a lot of really important, uh, supports, uh, for our services, like additional funding, um, which helped providers and states put extra money into their services, for example, to increase wages for DSPs for a limited period of time, or to provide retention bonuses for DSPs to keep them in their jobs. For a limited period of time. So that funding is winding down. We're also seeing the wind down of a lot of regulatory flexibilities that were helpful things like, um, paying family caregivers or respite care, or, um, the ability.

Lisa Tschudi: We'Ve talked on this show with some of the leaders in the movement in Oregon to maintain parents being paid caregivers. That's been a huge issue, and it is something that really helped address that, um, especially during the pandemic, um, that lack of non family caregivers, um, exactly.

Elise: And so we see states where this is becoming the norm, but we also see places where this is being wound down with the end of the public health emergency. And so all these things are kind of coming to a head right now. So we're still in this ongoing crisis. We are still, uh, sort of left with the lingering impact of the pandemic. And then we're seeing the ending of, um, uh, regulatory flexibilities and additional funding. And now we're in this place where we're saying our services are simply not sustainable at the current levels for how they're being funded. And so that's kind of where we are in this moment in time. And that's why the workforce shortage just continues to be a really big problem.

Lisa Tschudi: Yeah. And that is, um, I believe, May 11, um, when the public health emergency ends and all of those extra supports will go away. So, uh, people are really up against that right now. Correct. So what are some of the ways that you see, um, it being possible for us to address, uh, this care shortage, um, or shortage of DSPs?

Elise: Yeah, um, I think there's always, um, this idea that there are, uh, policies that we can support short of funding, and certainly there are a lot of policies that we support. One of them, like I said, is, um, just simply creating the ability to collect the data on a nationwide scale of what the DSP workforce is and what that looks like. Um, and that's a really wonky proposal. Um, but that is the idea to create a federal standard occupational classification for direct support professionals. So the, um, occupational code that's maintained by the federal government is a system that creates a code for each individual occupation. Um, and DSPs are not represented in that code, and so they're often lumped under broader, uh, terms, um, like home health AIDS, personal care AIDS, places where DSPs don't quite fit. It doesn't actually match up with the jobs that direct support professionals do or perform. And because of that, we don't have that way to gather that data across the country. And so one of our proposals is simply, hey, let's give us the tools to address this problem. We know it's a problem, but it's hard to address unless you can accurately quantify it. And so one of our proposals is to create that standard occupational classification for direct support professionals. Um, but most of uh, our proposals really simply come down to, we need more funding, we need more federal funding in the system. If we can't adequately fund the Medicaid program, then we can't address, uh, these problems that we talked about, like the ability to pay a living wage for direct support professionals. Um, and if we can't do that, then it's really, really difficult to retain the workforce and to recruit new people to the workforce. And we know that this is, um, a place where we're only going to need more people in the workforce. Um, I think the projections show that this is a really growing industry where we need more direct support professionals, uh, over the next few decades. And if we can't continue to bring people into the workforce, then we're going to have a serious problem. And wages is a really big piece of that.

Lisa Tschudi: Yeah. Um, wages can certainly make it impossible for people to accept these jobs that maybe would otherwise want to. But if they can make more and actually pay their rent and their own costs, then they are going to need to look elsewhere.

Elise: Exactly. If you can go down the street and you can go work at Target or Wawa or wherever that place might be, that, um, has a starting wage higher than what you can make as a direct support professional, which are really complex jobs. Right. Um, it's not a hard calculation for a lot of people to make to say, I'm going to go take that job down the road.

Lisa Tschudi: Um, let's get into a little bit what are some of the skills and, um, talents that DSPs bring to their job? Why is this not just an unskilled job that equates to flipping burgers?

Elise: Um, yeah, so the supports and services that are offered through, um, the Medicaid HCBS program are really varied. I talked earlier about how it's not really equivalent to say a DSP is like a home health aide or a personal care aide. Um, and that's because, um, DSPs aren't operating under the same sort of medical model that those other professions are. So certainly you might find a lot of overlap in what, for example, a home health aide does. So, um, certainly a DSP is helping somebody, um, with those pieces of getting dressed in the morning, um, keeping track of their medications, um, making their meals for them. All of those things are part of what a DSP does, but a DSP does so much more than that. Um, a really big component of this work is the community integration. And so it's making sure that, uh, the persons being supported have access to, um, social networks, to community programming, to, um, being able to, um, do things as independently as possible. So for every person that looks different. Right. So a big part of a direct support professionals job is making sure that those supports are person centered and uniquely tailored to the person. Um, and that might be making sure that a person can go grocery shopping and helping them create, um, the list, taking the bus to get there, making sure they have the tools and the ability to do that for themselves. It might be helping them to, uh, connect with family members to attend church in their community. It might look like employment supports. It might look like, um, facilitating a person to work, um, in a job for a few hours a week. So it really just runs the gamut. And it's such a unique job that really doesn't fit neatly in any of these other boxes that I think people want to sort of put it in. It really is unique and complex and unique to the person that they're supporting.

Lisa Tschudi: Yeah. And I think that last point about being unique to the person they're serving is really good to emphasize because it's really about getting to know an individual over time and how best to support that person and what their interests are and what lights them up or what they want to learn about or what they want to engage in and then helping to make that happen.

Elise: Yeah, I was going to say that's such a great point. And that's, um, really something that's been, again, exacerbated by this constant churn and turnover among the workforce. So these are, um, oftentimes the DSP is working with someone, they're working with them over a long period of time. And that's good for both the DSP and for the person they're supporting. If that person is building a relationship, establishing trust with that person, they're getting those really person centered supports and services. And then that person is constantly turning over every six months. It's really disruptive to that person's service plan, to their supports that they're receiving, and to really just their overall care and well being. So, again, we're seeing this problem of, uh, retention, uh, really just, uh, leaving long lasting impacts, uh, not only in the industry, but really unique to the person.

Lisa Tschudi: Yeah, it's a job where, uh, retaining an individual employee really matters, um, even more than many other jobs. It's really about that long term investment. And my family has been fortunate to have several non family employees at this point that stayed with us for multiple years, for example, and didn't turn over quite so quickly. Um, we've also had some that stayed with us only a couple of months or something like that. And they only ever thought of it as a little interim way to fill some time, um, while they were finishing up school. And then they were gonna get their, quote unquote, real job. Right. Um, and it it's it is really difficult, as the person requiring care or the family member to experience that kind of turnover in these sort of positions. And so that's one reason why these measures, like paying, um, living wage, at least, if not a really solid, middle class, comfortable wage, right. Is important and why. Um, the other measures that you talked about, I think you also mentioned in your letter, um, building some sort of structure for advancement within these positions. Um, it was phrased differently than I just said, but something like that, is that right?

Elise: Yeah, absolutely. And I think what you mentioned is um, a really big piece of that you said something to the effect of just doing this for a few months or a little bit of time until I get my real job, right? That's not what this should be. It should be seen as a profession. Um, and certainly there are those people in this field that have been here for 2030 years, right, because this is what they love to do. Um, but without, um, those sort of, ah, career ladders that we're building, um, we are not going to see people say, I mean, I think Wage is a big piece of it, but it's also that piece about professionalization being able to, um, offer, uh, training programs and pay people for their time to actually, um, learn from those programs. It's creating that career ladder. Um, so there is a proposal, um, that we support, there's legislation that's been introduced that would, um, create a grant program, um, through um, HHS, um, that would provide funding to create these types of uh, career pipelines for direct support professionals.

Lisa Tschudi: Yeah, I mean, I've thought for a long time as a parent that's um, a big need, um, because a it makes it more attractive for an employee to stay a prolonged period of time and make it their, quote unquote, real job and their career Aspiration. And b, um, in all truthfulness, um, what we parents often end up taking on is a measure of management and organization and administration that could be the aspirational job that somebody could move into potentially something similar to being the buck stop. Here's. Here person. The person that's, uh, going to be scheduling all the appointments, recruiting and scheduling other DSPs is going to be orienting when there's a new DSP is going to be, um, the fill in when other ones aren't available and organizing the medical care and making the phone calls to make appointments and all of these kinds of things. Um, is something that really, at this point, falls on family members one way or another. And when we get some support from caregivers that we can hire coming in, we're still in that management kind of role. Um, yeah, so it makes sense to me that that's a way there could be a uh, ladder to an Aspirational job that could be given uh, appropriate credit and pay and recognition, um, as a managerial level thing.

Elise: Absolutely. Ah, I think there's a lot of work to be done just in terms of making people even aware that these are jobs, um, because I think they're just not on everyone's radar. But um, then once people are in these positions, to support them to um, sort of move up, like you mentioned, into managerial roles. But unfortunately it's kind of one of those things where it's like a little bit of putting the carton from the horse. Right. Um, or the horse from the cart. I messed that up. But you know what I'm saying? Um, if we can't get enough people in these jobs in the first place, so many times people that are in these jobs because they're there, because they love it, because they see it as a career, we're asking them to take on these extra shifts.

Lisa Tschudi: Right?

Elise: We're asking them to take on all these additional things and then they're getting burnt out and they're getting worn down. And it's just a sort of vicious cycle, um, where if we can't pay people enough to get enough people in the door to create the system, then we're going to be continually left where we're just kind of trying to create this band aid over the problem. Trying to make sure these services still exist. Right? Yeah. Uh, one thing that um, we didn't talk about, which is that um, anchor has uh, been doing a survey every year of our members to look at what does the workforce shortage look like for you? Obviously we know it's a big problem, obviously we know it's the top priority for our members. Um, but what does that really mean? Right? And so we did our most um, recent survey last year in 2022, um, and we said, what is the impact of this um, on your services? And uh, I think 83% of um, providers we surveyed over, I think we had responses from over 700 um, providers across the country. And over 83% said we're just simply not able to take on new people. We're turning away new referrals. Um, and additional, about two thirds said we're discontinuing certain um, services and programs. So the impact of this is um, not only diminished sort of like quality and quantity of services, but in many cases it simply just means having to close your doors altogether. Because uh, the workforce shortage really is an issue of access at the end of the day.

Lisa Tschudi: Yeah. So um, I can definitely understand that being the number one priority is just number of workers in this workforce. Um, and from my own personal experience, that makes a lot of sense. And we've definitely in my family experienced um, where um, basically we made sure to set up our lives. So that my husband and I, and um, at this point also my um, the sibling to the one who requires a lot of care, my 3rd, 2nd daughter, um, that the three of us can share most of my daughter's care. Because any additional help that we find from non family caregivers and outside was never we, there was never enough people to find that there was any thought of both my husband and I working outside jobs. It was never sufficient and, um, well organized and, um, continuous enough that we could both work outside jobs. And so I, um, can definitely understand that need to just get people in the door and get people interested in these positions, um, first and foremost. And, um, there's some interface that we have to work out, I think, as a society, of what we need to find some agreement of what is the proper role between a family member and the caregiver, and when is it a paid caregiving job versus just what families do, quote, unquote. And I've had people tell me that what I do, which the state has evaluated at 314 hours of need per month, is, quote, unquote, just what moms do for an adult. And that's not ordinary parenting expectations. Somewhere in there, there's a line of, yeah, normally I would want to spend some time with my daughter. No matter what, I would do certain things for her. Um, I think we need to come to more consensus about the role between a family member and a provider. Um, I know it's kind of a hot issue in my state as to whether parents should be paid. And there are people who are powerful in regards to services for people with disabilities in the state who are philosophically opposed to parents or family members being paid, um, to care for their children. Um, do you have comment on that? Um, kind of what's the proper relationship and what would best practices be?

Elise: Yeah, no, thank you for sharing that. I think, um, I can't speak to any sort of anchor priority specific to, uh, states and paying family, um, caregivers, but I can say that what we have as a system is so untenable right. Like, all of these things should be working together and working coordination. Yes, we should have institutions for people who choose those or for whom that level of care is appropriate and is their choice. We should also have services provided in home and community based settings for people where that is appropriate and that is their choice.

Lisa Tschudi: It's time for a break. Please stay right here and we will be right back. Thank you for sticking around. We continue our conversation. So we were talking about this role between family member versus caregiver. Um, and do you have comment on what's best practices or what you see as appropriate between family members and caregivers?

Elise: Yeah, I think I was commenting more on sort of the system that we have, and which is that these things should all work together and they should not be in either or. So we shouldn't assume that, um, just because there is a family caregiver, that that is their only role. Um, that if it's appropriate for someone to receive care in the home, um, whether that be funded through, um, the Medicaid HCBS program, whether that is receiving care in their home from a family caregiver, that these are things that are appropriate for a person who chooses and it's appropriate to remain out of institutional care. And these things should be paid, right? These things should all work together. If someone chooses to go into an institution, if that's appropriate for them and for their family, that's the choice they're making, then that is an option as well. But if the state's, uh, only option for families is either institutional settings or at home with family caregivers, those aren't equal choices. And also if a family caregiver can't end up providing the support necessary because they're not paid, then where does a person end up back in an institution that's more costly for the state? That's not uh, an overall sustainable model, right? That these should all be options that are available to anybody, no matter where they receive care, no matter where they choose to receive care. But that if the only alternative is that we're forcing people back into institutional facilities, that that weighs more heavily on the state and therefore that's not really a good state policy. And so I would say that all of these things, all of these models of service delivery should all work together. Um, and that if we can't do that, then we simply don't have a sustainable system moving forward.

Lisa Tschudi: That makes a lot of sense. And the idea of choice, um, as I understand it, is really baked into most of these programs. And so it really is important to consider whether there's actually practical choices that are accessible to people. Exactly, um, yeah, that makes sense. Um, it's been interesting to me just the past six months or so since I started this podcast. Um, the kind of revelation about the variety of people that are under this huge umbrella called caregivers, right? And sometimes, um, coming from my perspective, where it was the amount of care that I was individually providing and really didn't have access to other people to provide was enormous. And then you have that, but then you also have somebody who's a caregiver who's um, feeling fine and they're still working their other job and they're uh, providing a little support 1015 hours a week or something, where they're driving for groceries or they're checking in on somebody. And I've been contemplating a lot where's that line between just what a family member does and just what we should continue to expect privately behind closed doors that we just do for each other and when is it uh, a job?

Elise: Yeah, I think you bring up a good point about sort of caregiving really broadly and what a big umbrella is and sort of the full spectrum. And um, I don't know that I can define where that line is, but I can say that I think a really positive development is the elevation of caregiving more broadly, um, just as an issue that we as a nation are sort of grappling with, right? Not only within our own families and communities. I think certainly that is something that people are more open to talking about. Um, but I also think just at a national level, um, we've seen, um, the President talk about the care infrastructure and caregiving. Um, just recently, April was, uh, national Caregiving Recognition Month for the first time. Um, the President signed an executive order, um, about caregiving. And it was really broad, like you said. I mean, it was from childcare workers to, um, HCBS, um, family caregiving. All of these things are mixed in there. And yes, they're all very different, and it's a very big umbrella. But I think just being able to continue to elevate this issue, to put it at the forefront of policymakers minds, while it is very varied across the spectrum, I think is a really good thing. I think the more people talking about this and acknowledging this is really positive. I, um, remember we were having a conversation with Senator, um, bob Casey from Pennsylvania, who is a really big champion for disability rights and disability services. Um, and he was saying something to the effect of, how are we going to get other policymakers and legislators to care about this? They're not going to care about this until it's on their front doorstep. And boy, will it be on their front doorstep soon. This is an issue that everybody can and should be able to relate to in some facet. And I think being able to sort of pick up on that wherever people are, whether that's taking care of an aging parent or whatever that looks like for them, I think being able to sort of tap into that. And then sort of expand out from there and talk about caregiving more broadly and what that looks like on a whole spectrum. I think that's sort of almost the way in there for a lot of people and a lot of, um, policymakers, too. So, um, I don't know that I had an answer for.

Lisa Tschudi: It comes back to a theme that, um, I'm finding over and over again, where, hey, this is universal. This is a universal human experience. To need care or provide care to one another. It is. That doesn't mean that in all cases, um, private families can simply provide everything that's necessary. It is something we have to tackle as a whole, especially as people are living longer, as people are living with conditions that they, um, wouldn't have lived with in the past. So, fortunately, people are living with, um, some of these things that require so much more ongoing care. And so we need to step up and collectively find ways to provide that care.

Elise: Exactly.

Lisa Tschudi: Yeah.

Elise: Um.

Lisa Tschudi: So, um, I've exceeded the half hour that I asked of you. Is there anything else that you would particularly like to add?

Elise: I don't think so. I, um, really appreciate, um, the work that you're doing and putting together this podcast. I think it's really wonderful, and I'm just appreciative for the opportunity. So.

Lisa Tschudi: Thank you. Thank you. I will put links, um, to Elisa's letter to policymakers, and I, um, would encourage everyone to go ahead and read it. And thank you very much. I'm Lisa Chudi, and this is love doesn't pay the bills, making family caregiving visible. If you've enjoyed the show, please tell a friend. Then you and your friend can both follow the show on Facebook or Twitter and participate in conversations about caregiving. Thanks for listening.