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>> KELLE MASTEN: Good afternoon and welcome to today's webinar entitled...

There's an echo. Sorry about that.

Welcome to today's webinar entitled "Recovery Through Personal Care Services" sponsored by SAMHSA and presented by the National Coalition for Mental Health Recovery. My name is Kelle Masten from the national Association of State Mental health Program Directors and I would like to thank you for joining today. Before we begin, I would like to go over a few housekeeping items. Today's webinar is being recorded. The recording along with the PowerPoint presentation slides will be sent via email within three to five days to all those who registered. However, you may download the PowerPoint slides now for your convenience. At the top of your screen where it says "files." Please click on upload file to download the slides. For those who need to use closed captioning today, please click the CC at the top of your screen and the transcription of the audio will be available to you. The caption box on your screen is customizable. Please adjust the display to your preference. Please know that all lines are currently muted. If you are having any technical difficulties during the webinar, please type your comment in the chat box and someone will be able to assist you. Please also type your questions for the presenters in the chat box, and during and at the end of the presentation we will ask as many questions as we can. At the end of the webinar, please take a few moments to complete a short evaluation for us. Please note that we do not offer CEU credits for our webinars, but we will send you a letter of attendance upon request. My email address will be available at the top of the screen during the evaluation. I would like to thank SAMHSA for allowing us to share this information with you today and, again, thank you for joining us. Today's presenters are Dr. Daniel Fisher, president of the National Coalition for Mental Health Recovery, and professor at University of Massachusetts Department of Psychiatry ‑‑ I'm sorry ‑‑ the Department of Psychiatry. And Drake Ewbank, a consultant with Lived Experience of the mental health system who served the peer population as an advocate and volunteer and then as a credentialed clinical and peer provider since the 1990s. Thank you to our presenters and we will now begin the presentation.

>> Thank you very much, Kelle. I look forward to this. This topic is particular interest, especially in today's era, because in the continuing movement of people out of institutions, there has not been sufficient supports for people in the community. And initially they, under the Community of Mental health Act, there was belief that clinical services would be sufficient to help people to adjust to life in the community. But through our peer movement and through our understanding of recovery of a life in the community, we have come to recognize that it's the relationships that people are able to form within the community that are crucial to people's adaptation to community life and recovery that involves these relationships. So we find that peers are especially well‑adapted to providing these services, and yet it's hard in a clinical environment to have peers provide the type of socialization, the type of mentoring, the type of coaching that people need when they're trying to get their life together. And I went through my own recovery from schizophrenia experience, and really it was the kind of supports I received from peers that was most valuable in my being able to develop goals and find relationships that were enduring and be able to stay out of the hospital. A psychiatrist, probably a difficult transition to make, but I think it's important that peers be in every level of society. So what is a personal care service? It's services that are provided in the community by non‑clinical personnel that can be peers, and it's most developed in the developmental disability community and for people with other disabilities. It has been underdeveloped in the mental health area, despite, as I said earlier, what people most need is social supports. They need people to accompany them in the transition from clinical supports to natural supports and Drake will say more about that. So typically, in most states, when you say to somebody on Medicaid, I want to get Medicaid support for people to receive social support in the community, but say, well, that's for people that have activity of daily living, ADL skill problems, that's for people in the disability community, people who use wheelchairs, people who are blind, they're the ones that need personal care assistants. But people in mental health, we don't provide that for people in mental health. But it is ‑‑ that's a glaring problem really, because it is very much needed in mental health.

So in the last 20 or 30 years, the mental health peer community has developed an understanding, what are the most important factors in people's recovery? And we find that having a choice and having hope about what those choices might be in terms of service and supports is very essential, developing resiliency, so that you can withstand the stresses of day‑to‑day life, developing independence, which comes from having a rich network of social supports, general well‑being, and empowerment, which is often an overused term, but really means having agency, having a self‑determination so that you make the major decisions in your life, and by developing the relationships, personal relationships with a PCA, this can help a person develop a sense of self so they're not always dependent on professional guidance. I'll give you a particular example. I'm working with a family and one member of the family is pretty much leaving their home and they're kind of fighting in the world outside, so they have a PCA for this person, actually hired privately, because it's difficult to get Medicaid support for it in that particular state. And what this ‑‑ what the family wants to know, well, what can this PCA do? And I said, well, they can help your family member to actually get into the programs that are in the community for support, because that's the missing ingredient. How does a person feel comfortable enough to enter into like a drop‑in center or a social club or someplace where they meet people and make friendships? So that made sense to the family and then they understood why they had hired this person. Now, I want to introduce really Oregon as a state that has overlaps probably 15 years, 20 years, developed a capacity through Medicaid to pay for this personal care assistance for mental health. And it has taken a lot of very detailed work. Once one state is able through Medicaid to reimburse for a service, then it can be solved by any state. So Oregon has set the precedent and has developed the procedures and policies that enable several hundred people to receive this service, unlike Massachusetts where there may be three or four people that are getting it, population 6 million people, they just won't budge yet in Massachusetts from the idea that people with mental health conditions cannot basically self‑direct. That's one of the criteria. I won't go into those details. I'll turn this over to my good friend Drake Ewbank, because he is from Oregon and he has personal experience, both giving and receiving these types of services. So, Drake, could you give us an idea of how Oregon has managed to develop PCAs for mental health?

>> DRAKE EWBANK: Well, I can kind of give you the story of how it started and how we actually get one in the state. Maybe that is a practical example, as well as the policy that created it. The Oregon Health Plan at its inception was trying to innovative, and one of the innovations was to create Medicaid services for people that were not simply disabled, and part of that expansion also included a bunch of service innovations, one of which was allowing a mental health system essentially to use personal care services to augment its clinical practices, to add on to those services that were based in the community and the case of PCAs, it was a way to empower consumers, people that were receiving services to hire somewhere to help them with basic tasks, in the hopes that the coverage of those tasks and the time spent with the person, which is in Oregon, it's 20 hours a month, would take some of the heat off the more mainstream mental health system, as well as provide community‑based support to the person. And this is basically coming out of the system's constant desire to try to spread out and provide community‑based networks of support that in some places are not served very well by simply having clinical services, but in Oregon they decided to widen that base by using the PCA program. This is one of the flagship moments for Governor Kitzhaber who was the one that developed health plan of using Medicaid money. He was an emergency room physician, so he had experience at the outset, so as governor he created a lot of very user‑friendly systems under the new managed care laws that took place at time. Anyways, to understand, I guess first what a PCA does, Dan did a pretty good job explaining how it relates to activities to have daily living. The one caveat I would say in this particular case is that the services, rather than just simply provider support for activities like medication management, helping someone with food, helping someone with other personal hygiene issues, for instance, that is sort of expanded to those things which the person would need due to their mental health diagnosis. And so that is kind of the criteria, that something in somebody's mental health framework requires that ‑‑ would benefit from having assistance as far as certain basic activities, and once you establish need for one hour a month of those basic activities, then you get another 19 hours of expanded activities, which are called instrumental ADLs, which include everything from shopping for food to helping someone get to appointments, to doing light housekeeping, to... but what it ends up being, I think, and the successful part of it, as far as I can tell, is what Dan put his finger on exactly, which is establishing relationships. Almost every situation that has a positive outcome that I have seen in the PCA program is where there's a good rapport between the person providing the help and the person who essentially in the Oregon system is the employer, which is an interesting aspect of it. It has some resemblances to the developmentally disabled system in that when a person in the DB system engages services, they are actually the employer. Our state doesn't go as far as to issue individuals' federal identification numbers, but the system actually does that, where they create their own corporation and that can become the employer. This sounds complicated, but what it basically means is that the state is the payor and pays the PCA, the person that provides the services, and the person receiving the services simply signs their timecard. One of the great benefits of this is that there is very few things like progress notes and very few things that are otherwise not just simply part of the help that is provided and the support that is provided. This open‑ended arrangement, a number of possibilities that Dan also has mentioned here, which support values that range everywhere to recovery to keeping a person in their home and out of the hospital to establishing friendships peripherally by providing somebody with the access to the community that they wouldn't otherwise have. So, that's how the PCA program functions. That's kind of its optimal set of values that is in play if it works well.

>> DANIEL FISHER: I have a question, Drake. If you don't mind. It's from a participant who said that they thought that the program was dropped in 2009 in Oregon. Wonder how they got that impression? Is there a dip?

>> DRAKE EWBANK: What has really happened in Oregon is that it's under‑used. People... how do I explain this? There was no central location for the state to manage this program or educate clinicians on this. So like there is no central ‑‑ currently, still, there's no central registry for PCAs, so basically the program only survives by word of mouth and through ‑‑ and before quite recently, last July, actually, willing clinician that is were willing to sign as case managers for the services. The services are basically a year's worth of authorization for 20 hours a month, and it has really very simple assessment checklist of needs. But even with that simplicity, the program was underused because clinicians didn't understand it and still don't, and actually at one point we were prevented from actually educating people because the state wanted to manage that themselves, but they only assigned a single individual as a point person at the state who didn't have the time to do that. So we basically did ‑‑ the program has expanded on a case‑by‑case basis. So I think a little of 500 PCAs or...

>> DANIEL FISHER: I think one reason, this is my hunch, for the under‑utilization is it requires a paradigm shift. People need, in the clinical world, to understand that recovery is more than a clinical activity. But that requires on the part of clinicians an acceptance of their own limitations, and I myself am a peer but also a psychiatrist, and I know as in my role as a psychiatrist, I can't help people with their socialization. I wish I could. I remember asking a consumer that I was working with, I was their psychiatrist, I said, how do you get ‑‑ what do you get from the peer that you can't get from me as a psychiatrist? And he said, Dr. Fisher, you can't just go out and have a pizza with me, can you? [chuckles]

I said, gee, I'd like to, but you're right, I get 15 or 20 minutes with you and we wouldn't even get one slice. So, yes, this same woman also asked another interesting question, Drake, and that's... does a person have to... if a person has a physical disability as well as a mental health one, are they eligible for both service hours? Which is an interesting question. I don't know.

>> DRAKE EWBANK: The answer is yes. And even in the DD system the answer is yes. What would happen is it would actually be easier to clear some of the initial hurdles for the services and mental health because you actually have co‑occurring physical disabilities that you have to deal with that may have a mental health impact, so it actually fits well together and it adds a whole bunch of hours. So...

This system should like this service much better than it does, because it really extends their ability to support people in their home, in their community, and provide them with something more interesting to do than go to appointments. I mean, you're very correct, Dan, about the paradigm shift. And often clinicians don't have the time. You have clinicians out there cleaning out refrigerators and acting as the best friend of people that they basically only spend a half hour with or an hour with every month. So it's kind of a heavyweight that gets taken off the clinician's shoulders when they have somebody to interact with on a regular basis that they trust.

>> DANIEL FISHER: There is an economics to this also, having worked in the community mental health center, there's productivity standards that the clinicians are supposed to fill.

>> DRAKE EWBANK: Not only that, the coverage is about 10 PCA hours to what is built here. You get 10 PCA hours for one clinician hour. So it's ‑‑ and a lot of things in the system, the most successful things are personally intensive. And the most expensive things are the least personally intensive. So it's ‑‑ the system is a little on its ear that way about how its resources are allocated.

>> DANIEL FISHER: Here is another question. This is exactly the kind of support a friend of mine needs right here and now in Washington, the state of Washington, I'm pretty sure. How can I advocate to get this program running here? I'm the disability rep for the Washington area agency on aging.

>> DRAKE EWBANK: Without being too silly about it, you probably want to plant both feet on the desktop of the Medicaid liaison in your mental health program at the state level. That is the person that would be in charge of changing your waiver that would allow the state to build for those services and reconfigure those services under their waiver.

>> DANIEL FISHER: What type of waiver... let's go back a moment. You mentioned waiver as if everyone understands what a waiver is. My understanding ‑‑

>> DRAKE EWBANK: Sorry about that.

>> DANIEL FISHER: That's okay. My understanding of a waiver is it allows the state to bill for Medicaid services that otherwise are not covered without a waiver. So what kind of waiver does Oregon have that allows them to bill for the service?

>> DRAKE EWBANK: Medicaid has encouraged people to innovative on top of the basic set of services they might be required to provide, which are usually a fairly minimal amount. The waivers are sent for approval and there's different waivers having to do with different emphasis on how ‑‑ what kinds of extra services that you have. There's rehabilitation waivers, there are home and community‑based services waivers, and there are a number of different flavors that are developed by states under the same essential Medicaid rules that add and innovative, essentially, based upon the total approval, of course.

>> DANIEL FISHER: Do you know what waiver Oregon has?

>> DRAKE EWBANK: Well, there's actually three waiver that is PCAs are able to work under. So you can have more than one waiver in a state. So, in Oregon, there is a home and community‑based services, there is a rehabilitation option, and then the DD option that is another waiver altogether that serves that population. The larger meta‑category of PCAs is personal support workers, which is a larger category that also serves other populations that are almost all physical medicine, for instance.

>> DANIEL FISHER: And another question is: What is an iADL?

>> DRAKE EWBANK: iADLs... activities of daily living are basically stuff that you need to do to get, as one person told me, the peas on the knife of living, or essentially function on a daily basis. So the basic ADLs are, you know, things like keeping your ability to feed yourself, house yourself, take care of any medical needs you have, transfer in places where people have those challenges, but the iADLs expand on that and they're more activities where there are processes of living in the community, I guess that would be a good way to describe it, or things that would be extra to those basic Pavlovian needs. It's expanded to things like socialization. Let's see what else. I can actually pull out a list I think here.

>> DANIEL FISHER: They're actually on the screen right now, Drake. I put the slide back up. I sort of had skipped by it, but you prepared this on the screen so people can see that.

>> DRAKE EWBANK: This isn't a comprehensive list. There's transportation to appointments or other necessary destinations, meal planning, helping with light housekeeping, helping them set up medications if they have a medication issue that they need to help with, you know, completing their... getting whatever meds they need to take each day. It can help with food preparation, helping people choose the right food, for instance. Budgeting is often including. And the last one is cognitive support. It's kind of an odd category that they have kind of thrown in here, which is basically helping somebody navigate outside ‑‑ to function in their lives, navigate that process by having somebody that is there to help them sort of stabilize in their interactions with the public and interactions with other systems that they might come in contact with. And what it ends up being is like helping get somebody fill out applications, get somebody to understand what the function of different agencies are. It can even include somebody not understanding what's going on with how their neighbor is bugging them. It takes a lot of different forms. But essentially you're a support system, when somebody is having some cognitive difficulties around their environment. So that's how it's been defined to me at least. And also ends up in having a socialization element to it.

>> DANIEL FISHER: Decision making is a big one. Typically people are said or told they don't have the capacity to make decisions if they have a mental health condition, and this decision supports is something I think is very helpful. I have someone to talk through... you know, should I go to this social support? Should I try a job? Should I... they're more than therapy issues and more than case management issues. And here is another ‑‑

>> DRAKE EWBANK: Environmental adjustments. Go ahead.

>> DANIEL FISHER: There is another question that has come up. How would folks working in Oregon better help consumers access PCAs, I work in a community behavioral health center and clinicians are often on board with this idea, yet we run into issues actually finding individuals that can provide the service. I wish there was a registry of sorts or someone we could consult with.

>> DRAKE EWBANK: As a PCA I would like to say, we do too. Comagine is over the authorization process. It's a third party basically focused on getting people eligible and finding them PCAs. So essentially the process has kind of started of indexing who can provide the services and how to access them, how to get to them and connect with them. Comagine has essentially taken the place of the individual case managers. And contacting ‑‑ if you need specific information, contacting Comagine, C‑O‑M‑A‑G‑I‑N‑E, and there's a contact number on the web page, Comagine.org for Oregon. And get in touch with them and you can actually find that. Or asking your case manager to contact them. They should have been ‑‑ their agency should have already heard about how to get in touch with Comagine if people need PCA services. That's actually improving.

I also see a question here about how PCA services differ from peer specialist services. I would like to answer that at some point, but if you would go ahead and finish what you were going to ask.

>> DANIEL FISHER: I was just going one‑by‑one through this. I contacted Comagine actually in part of my research on what Oregon was doing, just as an outside person and also for preparing for this, and Comagine actually said to me all they're presently contracted to do is quality improvement. They didn't say they helped people find a PCA, but maybe that will change or maybe it has changed. That was a couple months ago.

>> DRAKE EWBANK: in the process of changing it, I believe, just the fact we now have a list of all the eligible PCAs is a big step. That effort you made, I actually provided Comagine and the clinic with your list that you requested under the documentation.

>> DANIEL FISHER: I'll be honest, I don't want to... well, good. If people are wondering about advocacy, I inadvertently helped become an advocate for PCA services in Oregon, just by the questions I was asking, and I went from one state official to another and said, tell me about your service. Tell me about your service. How many PCAs are there, who are they? Gradually, I must say it took three or four different contacts, but I found somebody who could produce a list of the PCAs in the state of Oregon and supplied that to Drake and he then supplied it to Comagine. That's a ‑‑

>> DRAKE EWBANK: Should have had it already, yes.

>> DANIEL FISHER: That's an illustration of advocacy and action, people like the person from state of Washington was asking. Go to the state officials and ask questions of them, the first thing you do. And by the way, if one state ‑‑ I mentioned this earlier, but I want to reiterate it. If one state can get an innovative application of medication reimbursement, which has not previously occurred, then that becomes a precedent that any state can do it. The future other states can refer to Oregon. They don't have to go through the entire federal process of getting the approval. They can rely on the approval process that Oregon went through. So Oregon has done a terrific job of national advocacy by establishing this. Sarah has asked... if so, how would advocates go about requesting? Hmm... let me see. Must be referring to something else in the question.

>> DRAKE EWBANK: I think that was how you get it included. I think you were actually just answering their question.

>> DANIEL FISHER: Yeah, how you get included. The same person is from Vermont, said that Vermont has this program and a PCA registry for developmental disability. Let's face it, development disability ‑‑

>> DRAKE EWBANK: We have one in Oregon as well.

>> DANIEL FISHER: Of the mental health world.

>> DRAKE EWBANK: There is an extraordinarily robust registry for personal support workers in workers in Oregon. It's an oversight at this point.

>> DANIEL FISHER: They do a different kind of activity. The other one is do boundary issues emerge? And if so, how do you handle them?

>> DRAKE EWBANK: This is one of my favorite questions and I know Dan gets it a lot.

>> DANIEL FISHER: I get it a lot.

>> DRAKE EWBANK: Usually hinge around disclosure, and to be fair the PCA relationship is a lot less formal. It's not bound like, for instance, social worker type ethical standards, where you're not allowed to have a dual relationship. In the case of PCAs, it's almost impossible not to have some rapport with the person, unless you're being fired, I guess, which is person has the right to do. Which is mentioned in one of the questions later here.

But the informality of it, it's usually someone that the person knows or trusts and so that naturally leads to not just disclosures but simply, you know, a lot of personal interaction. I don't know how else to put it. And the person doing the services has I think the choice as well as the person receiving the service as a choice to set that boundary. And I've never had it really be a problem in my experience, but I know that that's a concern that is often expressed. Again, this is ‑‑ you don't need to know a lot about somebody's issues and private stuff to be able to clean their apartment every once in a while or take them to the store you know, personal normal interactions with them and have a nice supportive relationship without having to breach anything that, for instance, is part of their mental health stuff.

>> DANIEL FISHER: It's interesting this issue...

[ overlapping ]

>> DANIEL FISHER: Yeah, this issue comes up with peer support too, by way, which I'm sure you're aware of. And actually this could have happened with a PCA. I was actually like a co‑supervisor of peers early on here in Massachusetts, and there was a peer, and the consumer that he was supporting, one to two hours a week, they got to be really good friends, because they both were kind of isolated in their world. And the hours kept expanding and expanding, and they were fixing meals together and going to the restaurant. Finally I said, you know, it seems to me you are becoming friends. And the peer said, yes, I am his friend. Unfortunately, you probably have to make a choice, will you be his friend, and the open‑ended sense of being a friend, or will you continue as a peer who will be friendly but not be their friend?

And actually the gentleman decided he wanted to be his friend, so he stopped being his PCA ‑‑ I mean, his peer. And I think it is sort of a challenge, because you have people that are lonely, especially now in this era of COVID. And how we can provide them with the friendly support, but they don't necessarily have a full friendship or fall in love and say, we'll go out on dates. It's an interesting question. And I wonder, do the PCAs have ‑‑ though is a question that came up ‑‑ a third‑party that they can appeal to, like the person receiving services appeal to, might appeal to and.

>> DRAKE EWBANK: They can also create agreements between themselves and the PCA as to how the relationship should work. And sometimes that's encouraged, a person has specific requirements and they aren't particularly ‑‑ it isn't somebody that you know or ‑‑

Often people that people personally know or know through other people who are getting PCA services, that's how it works here. The informality is here if people want it. And it isn't particularly intrusive that I have found, but if somebody is just there to do the work fairly narrowly, some people that's all they want and that works just fine too. But I found most of the time that the relationship blossoms into an ever‑widening amount of supports, both helping people access other supports and also just developing rapport and trust.

I don't know quite how to ‑‑ if trust is violating a boundary, then you already are kind of in trouble in the system. That is one of the problems with the clinical model, is that you can't actually treat the person as a person you can go have pizza with, because it's essentially an ethical violation. And I would never, ever hesitate to take somebody to a pizza parlor if that's the meal they wanted to eat that day, if they were my PCA client. So I don't know how to ‑‑ I don't know how to reconcile those two except to say that the informality actually is usually a benefit rather than a harm, and the system usually assumes it's a harm, so...

>> DANIEL FISHER: I think it's terrific. I'm just raising an occasional situation that, you know, where ‑‑ who would the third party be? Who might be the third party.

>> DRAKE EWBANK: And the case manager is aware of that. This case, probably by the time they're done, you go back to Comagine if you're having problems with a PCA. And there are things that can ‑‑ I mean, the consumer has ‑‑ this is a at‑will state and they can fire the PCA without cause. And, in fact, I know people that just lose it one day and decide that's it for their PCA, and probably it was a bad idea to fire them, but they do that, and they are perfectly empowered to do that for themselves or asking a third party to do that. So it's totally...

>> DANIEL FISHER: I think this is an important point and I'm glad it was raised. It's probably one each person will have to work out with their ‑‑ with both the PCA and their case manager. This brings up another question I haven't seen yet.

I'm expecting it. What is the relationship between the parkway and the formal clinical system ‑‑ between the PCA and formal clinical system? How do they communicate? How do they relate? Especially since they're in different paradigms often.

>> DRAKE EWBANK: As I'm trying to portray this in the light that it actually occurs, it's actually beneficial relationship in most cases. Because in Oregon, by the time a clinician has found the person, the PCA and that relationship is working well, part of the job is keeping the clinical folks informed of the status of your client and let them know early on if they're starting to meltdown or things are starting to go south.

It's a valuable way to get people early help. So clinical people tend to value that. If somebody needs to be seen that day and can't get to the clinic because they're afraid to go out of their house, having somebody that can go over and get them to the clinic that day can mean the difference between extended stay in the hospital and, you know, happily ever after. And that's an enormous benefit, because it saves you a lot of the trauma of not having ‑‑ people not having services they need at the time they need them.

>> DANIEL FISHER: Very good. Another question here.

Can a person who already receives personal services for physical health, can they get more hours for their dementia? I think you answered that earlier the other way, that they can add physical ‑‑ can they go from physical ‑‑

>> DRAKE EWBANK: As long as the dementia spans into a mental health diagnosis of some sort, it absolutely can be. You can absolutely get extra hours.

>> DANIEL FISHER: Cognition, certainly, the cognitive supports would be valuable. Are they using traditional healthcare workers as PCAs or PCSs?

>> DRAKE EWBANK: It's a separate entities. The peer support people go through the traditional healthcare commission, and the PCAs go through the Home Care Commission. So you work through a different set of standards.

That's one of the reasons that a certification is not necessary to be a PCA. In that sense it's a lot simpler and it's a different track. It's mostly daily living supports rather than peer interventions or community health interventions.

>> DANIEL FISHER: The next question is: Is this only for Medicaid recipients or Medicare as well? If Medicare is not included, is there something in the works for this?

Those who don't qualify for Medicaid also have a great need for these services. Good question.

>> DRAKE EWBANK: In our state they have two avenues for a Medicare person to become dual eligible. The other is the Pickle Amendment, which qualifies somebody based on the amount of income they had when they became disabled. And it's a complex thing to try to explain. The other one is a system that allows you to get Medicaid if you can work four hours a month or more. It's a system to the employed disabled, essentially. And that will allow you to access Medicaid. But other than that, Medicare has ‑‑ for instance, counseling services not coming from a licensed psychologist or psychiatrist, you have to have medical personnel on site when providing counseling services. It's one of those things. Medicare does not have an in‑home care component except for like they can get you a nurse for two days a week or they can get you somebody there to do transfers, which is home care stuff, but it has to be linked to a physical disability, in which case you would be eligible for essentially outpatient care from the medical system.

>> DANIEL FISHER: Sounds lining a need for advocacy, unfortunately, at the federal level, to change a Medicare rule like that, you would have to have advocacy at CMS itself.

>> DRAKE EWBANK: Yes, and they often have that problem. Medicare is strict about things. Medicaid has some expansions that are not available to Medicare.

>> DANIEL FISHER: Some states have done the ‑‑ some states have done the expansions more than others, too.

Oregon, like Massachusetts, has a fairly generous expansion of Medicaid services, but ‑‑

>> DRAKE EWBANK: I thought at one point that states don't have to provide mental health services at all under Medicaid, which is interesting, because Utah at one point I think was going to try to opt out of providing a state mental health system.

I don't know what you do at that point, if the Feds step in or what, but it's ‑‑

>> DANIEL FISHER: I think it's up to the state.

>> DRAKE EWBANK: It's counterintuitive at times.

>> DANIEL FISHER: There is an alternative conference coming up where we have a section on advocacy, and we'll have further discussion of PCAs probably at that conference.

So stay tuned for that conference. Any outcome studies of the Oregon program? Good question.

>> DRAKE EWBANK: I think there are some early studies. Rather than having a study, per se, they ran a program on training people how to hire.

And configure their relationships with PCAs. There was a big federal grant. I don't know if that had data specifically that came out, but they went out and actually tried to show people how to use the program, because they considered it ‑‑ the Feds considered it at that point an innovation. And this is like 2005 or 2006. So there is some stuff out there but not ‑‑ I mean, it would be the same kind of things that would be available, for instance, peer support... there's a lot of anecdotal sort of information and a lot of positive outcomes that people can point to, but not these peer reviewed studies that would be for a research base.

>> DANIEL FISHER: You make an interesting point, Drake. That is that peer support, which does carry out some of these functions, peer support often does carry them out

Although it's under a clinical umbrella, and oversight and labeling. A lot of medical clinical aspects. But peer support actually has been classified as evidence‑based practice, so it actually has been elevated to that level. Maybe it's possible for PCAs to qualify, you know, they reach some of the standards that peer support has reached.

>> DRAKE EWBANK: Where I am, the evidence‑based practice regime has kind of been depreciated over time, in that everybody kind of went out and got a three peered reviewed studies and came back and the system was doing evidence‑based practices, because it essentially looked like the thing they were trying to say didn't work before evidence‑based practices were put in place, but the first evidence‑based practice in Oregon that was registered in the state as an evidence‑based practice was peer‑run drop‑in centers. And even with that ‑‑ even with that evidence base, they still wouldn't fund enough peer‑run drop‑in centers. That's ‑‑ we have outcomes, we have excellent financial reasons who adopt a lot of these services. Recovery is one of the few places where budgets go down rather than up or stay the same as maintenance over time. You know, it's the Hotel California model where everybody checks in but never checks out, so the budget never goes down because nobody is recovering out of the system. So all those things added together have never been picked up. The franchise has never been picked up in a meaningful way here, and it's unfortunate because we have an outstanding number of peer advocates and people doing service innovations. We had the first mental health service brokerage here. You know, I can go on and on about it. But you have to get ‑‑ the paradigm has to change, as you said, you have to have a system that supports expanded definitions of what help looks like, and my personal feeling is you have to have an outcomes‑based results‑based system for us to get anywhere. Because we can actually produce results. We just can't seem to accrue support amongst clinical administrators. Which is a different ‑‑... a different model.

>> DANIEL FISHER: One of the reasons we're doing this webinar is to educate people about the importance and the feasibility.

There's a question here. How does the role of PCAs differ from other direct care workers such as housing counselors, care coordinators and home health aide?

Good question.

It probably would be closer to home health aide. The one difference it is ‑‑ it isn't goal specific, it's written as a per diem kind of service. So you don't have to produce progress now. You don't have a specific result to produce, the billing system is different, and PCAs generally are only required to pass a background check to be able to manage ‑‑ there's a safe set of ethical standards that also govern peer specialists and traditional healthcare workers, that they have to be able to adhere to and they have to be able to do the job taking care of the person under the terms of their plan. If you can build those three things, that's all you need to be a PCA. Most of the other jobs, possibly home health aides have some kind of licensure or certification or credentialing that goes with them. Here you just have to be able to do the job and pass a background check.

>> DANIEL FISHER: Here is another one. What is the difference between ‑‑ it's interesting. They put PCS and PSS, and you might say a little about the term PCS, personal care services, and PCAs, and then maybe compare those to peer support services.

>> DRAKE EWBANK: A PCA would be equivalent of PCS. Those are both individuals. Peer services I don't think has an acronym. Personal care services or personal care attendant or assistant.

>> DANIEL FISHER: So the PCS is just really a description of the service itself, whereas the PCA is the fern who is delivering the service.

>> DRAKE EWBANK: Generally the PCA ‑‑ here it isn't used as PCA. Usually it's PCA services. One thing I would like to mention is that you were talking about... oh, gosh. There are a number of expansions of this that are being worked on, when talking about things being opened up a little bit over time. That I did want to mention this and we talked ‑‑ I talked about this before, is that under the home and community‑based services waiver, there are habilitation services that include qualifying people on only second tier ADLs. We have two of those that a person meets, like budgeting or getting to appointments or managing their medications, or a number of criteria that are open‑ended and look a lot more like peer services than almost anything I have found. And those can be provided what they call recovery assistant. Which specialists would qualify for immediately.

So I just wanted to mention that, is if they need to relax the criteria a little bit, even in Oregon, which is something we're trying to do, essentially the task that peer specialists provides without all of the administrative and clinical badge that is usually required of people is possible. And that would be a real advantage. Because peers usually are not interacting with people as a clinical therapeutic tool other than the overall impact on the person's life. I think we were discussing earlier about how it is peer services or PCA services, you know, part of Medicaid, if it's dealing with somebody's environment.

Really you can have somebody that is trauma ‑‑ whose problems are trauma‑based, where the environment caused their problems. It's reasonable to assume that the environment and fixing things in their environment and supporting them in their environment can help them out of their problems, and that support has at least as much therapeutic value as counseling or drugs, which is what they're competing with, so...

>> DANIEL FISHER: There's another question here. It may be a comment. Why aren't... why aren't we connected with the Oregon Department of Human Services/seniors and people with disabilities/Oregon home care commission/DSW‑HCW? Why aren't we connected with them?

>> DRAKE EWBANK: The PCA program is. PCAs are regulated by the home care commission. So if there's a question there, the peer specialists, however, can come out of the opposite equity and inclusion, which is the traditional healthcare workers commission.

>> DANIEL FISHER: I actually spoke with the director of the Oregon home care commission in one of my calls, and they were aware of the program, but they didn't have details on it. Which was interesting.

>> DRAKE EWBANK: We are very misunderstood and very small compared to the other 33,000 people that they manage. Part of that is the 20PC people because they're mental health, like we don't have a billing system that is the same, we don't have a registry.

We don't have... we have different standards of care. So, it's... we're...

>> DANIEL FISHER: You need more of a voice in the system.

>> DRAKE EWBANK: Yeah, there is no centralized organizational element except the approval process. We home Comagine can hook people up. They can't do their job right now because there aren't enough PCAs. And one of the other things, 20 hours a month where the home care job is usually ‑‑ it borders on full time.

>> DANIEL FISHER: Hard to get people to work for just 20 hours a month.

>> DRAKE EWBANK: You're allowed a maximum of 140, and even that, at a good wage with benefits, because of the union and with retirement, because of the union actually, it still is 20 hours short of a whole month's work.

>> DAN: Somebody on disability themselves, I wonder if it would fit in their income, maximum allowance in 20 hours. You know what the hourly rate is about?

>> DRAKE EWBANK: 15.77 right now and going up. You have to be on the negotiating team when they first ‑‑ they moved the salary from ‑‑ or the wages from 9.25 an hour to 13‑something an hour.

They progressively increased it every year since 2012.

>> DANIEL FISHER: So that's per month, it would be roughly $300 a month that a PCA could make.

>> DRAKE EWBANK: After taxes and everything else, it's about 250.

>> DANIEL FISHER: It's a way into employment overall I would say.

Here is another one. My friend always had trouble keeping PCAs and the agency never ever addressed the behavioral health. She was to have a maximum number of hours, but never got it because she had anger issues due to TBI from stroke? It was far more complex. She is now in a group home and things are even worse. You get a PCA like this even in a group home.

>> DRAKE EWBANK: No, because they're siloed services.

The TBI system has its own providers as well. And most of the TBI populations are not treated very well as far as we could tell even in good systems. The difference in behaviors, caused by the brain injuries, are not accommodated very well. So holding them accountable for being angry, it's a little bit at the same time you're trying to help them with this, it's a little counterintuitive.

So that population has special needs and the provider element is really not very well designed at this point.

>> DANIEL FISHER: What are the qualms for PCAs, how are they trained and supervised? What is the feedback loop they find themselves over their head of the client? It's actually three separate questions. How about, what are the qualms for PCAs?

>> DRAKE EWBANK: I think the difficulty, the work sometimes ends up being cleaning, trying to keep people from getting evicted from their apartments because they're constantly causing health hazards. That becomes tedious to people unless they really love janitorial work. For instance, I had a client at one point that had colitis, and that was a nightmare.

So that can get tiring. Somebody that is demanding of your time, as it is 20 hours a month, and if somebody needs you all the time for short amounts. If somebody needs you for basically 40 half‑hour segments, it's not very efficient. And, you know, they just need to ride to the doctor and don't need to stay, that kind of thing, it can be a little bit uneconomically sound.

>> DANIEL FISHER: When I read that question, I couldn't understand if it was qualms that PCAs have or qualms that people have about PCAs.

>> DRAKE EWBANK: The complaints usually are the person isn't on time or unreliable or does stuff they don't ask for, isn't available enough. Those are pretty common complaints.

>> DANIEL FISHER: Like a PCA give a home phone number or cell phone, would they give that so people could call them at any time?

>> DRAKE EWBANK: I doesn't know anybody that doesn't. How's that?

You can set limits and not answer the phone. I've done that occasionally with somebody, especially abusing a cell phone. But usually I personally try to answer calls simply because if it really was an emergency, I didn't want to be the person that had to answer the question, why didn't you pick up?

>> DANIEL FISHER: I think you already have gone over this, the training and supervision. You said there is some training. How much training does the PCA receive and what type of training?

>> DRAKE EWBANK: Very little. The competency is around the ADLs. As long as they can help with specific tasks. Things people already know how to do, driving, helping people get to appointments. So you could do those tasks and pass a background check, there is no training ‑‑ though training would help. I'm not trying to dismiss its value, but I'm saying to get in at an entry level is a PCA, often because it can be acquaintances and occasionally family members, that it isn't a high bar.

>> DANIEL FISHER: This brings up another question that was on the slide. I think we should show the slide. Which is the types of ‑‑ though is a summary of PCA responsibilities, and one of the responsibilities that you have listed here is crisis supports.

Help me understand, how can a PCA help with a crisis.

>> DRAKE EWBANK: Well, if somebody is in crisis or doing badly or deteriorating, that is something that generally will be reported to their case manager, so that they can make arrangements for more or different services.

If it's an immediate emergency in a crisis, sometimes you're the first person that they will call, and it is absolutely essential that you be able to access emergency services, as well as emergency mental health services, crisis supports.

And I've taken a few people to the emergency room a few times, because that's where they needed to go and that's where they wanted to go. And sat with them, which is a great he, because often they will let people sit there two or three hours before they're evaluated and processed into a mental health unit.

>> DANIEL FISHER: I would imagine also that PCAs could at times help prevent a situation from getting to a crisis.

>> DRAKE EWBANK: If you have a good relationship with the person, usually you can talk them down a little bit in situations where they're starting to get excited or starting to sort of go south, sort of a cognitive element that is helping people orient themselves when they're afraid of a neighbor or something like that, being around to provide that support and put out the fire as it were.

And getting them to help in some meaningful sense, you know, knowing that you can access that help through the PCA also tends to be an advantage to everybody involved.

I think almost all the low‑level crisis benefit from having somebody to balance ideas off of and what is going on, having somebody to talk to, and that is totally within the PCAs' scope of work.

>> DANIEL FISHER: I know that as a psychiatrist, I used to work in an emergency room and I would be much more comfortable than somebody, you know, that was in the distressed state.

I would be more comfortable having them go back to their apartment, if I knew somebody could be there with them, so they weren't so alone. That may be more comfortable. And ideally I could even talk to that person and say, you know, this is the trauma for more service. It's too bad that 20 hours is a problem. Because I imagine at times someone in a crisis would need more hours. Is there ever a time that you can get more than 20 hours?

>> DRAKE EWBANK: Yeah, with critical need you can double that, or you can ask for the number of hours you need. I've had people that I worked with that I split 40 hours with another PCA and that worked pretty well. And also I wanted to mention, talking about having somebody there, I've had somebody that was in crisis and diverted from the hospital to a peer respite, which they have some of the clinical elements that are community‑based around here have, have set up a couple peer respite apartments. I could take them there and they were good until 9:00 in the morning and they basically turn people out later in the afternoon, but I could pick up where respite left off so they would have somebody with them all the time. And that worked really well.

>> DANIEL FISHER: Are you saying that Oregon has some peer‑run respites?

>> DRAKE EWBANK: It has had a couple of diversion based apartments they take people to. And they have been fiddling around with this. There was an agency called Laurel Hill that basically bought an apartment house and used two of those apartments for peer respite. But it would be from dusk to dawn type stuff.

>> DANIEL FISHER: Peer staff but not peer‑run agencies.

>> DRAKE EWBANK: They were not peer agencies but they basically had peer specialists to stay the night with the person in one of those apartments.

>> DANIEL FISHER: I know Kevin Fitz has been strongly advocating for at least three peer run respites in Oregon.

>> DRAKE EWBANK: We did such a good job testifying for that that one of the Republican legislators asked to have one extra put in his area and was able to vote up the funding for it.

>> DANIEL FISHER: So it may happen. Like Christmas in July here.

>> DRAKE EWBANK: And this is different. It's another topic, but peer‑run respites, by the way, would, it seems to me, would complement very well this PCA approach, because they assume their philosophy.

>> DRAKE EWBANK: Yeah, and the idea there is trustworthy low level supports and you can go to in crisis and have people go to in crisis. And that kind of blanket safety net is something the system has been missing for years. And basically until now they have had two speeds you know, at home or in the hospital. And being at home alone usually deteriorates people enough that they end up in the hospital, if there's nothing in between.

>> DANIEL FISHER: I can imagine people going to a respite at night, because that might be a pretty difficult time period, but back to their apartment during the day, so they could have a PCA there with them during the day. It just seems like the two would operate together very well.

There is a question again about state certification. I think what you side is there is no state certification process for PCAs?

>> DRAKE EWBANK: You get a Medicaid provider number. You do not have to pass through classes, per se, but, again, let me emphasize that I am not a union here, and other places have continuing education courses and other things that you can basically take part in that are excellent help for people trying to deal with people that have ‑‑ you know, people trying to help people that are in extreme states, having skills in that regard to be able to help people down off the cliff is a really useful skill to have, as well as other things. So it's not so much that it's against training, but the basic qualification is only a background check, being able to do the basic job and following the ethical standards of states. It's a very easy entry level job, but to do it well, experience helps, anything that you bring to it that can establish rapport with the person is going to help as well. I mean, there are people better getting along with certain people. There are certain people that fit well with certain other people, and those are ‑‑ those relationships are the most valuable as far as I can tell.

>> DANIEL FISHER: I don't know how familiar you are with emotional CPR, but seems like that would be helpful training for PCAs.

>> DRAKE EWBANK: Absolutely.

>> DANIEL FISHER: We should look into that.

I think we already have gone over this ‑‑ the PCA versus the PCS. How do I go about starting a PCA? I guess meaning PCS. Someone wants to know how to go about starting it. I heard you say earlier to put your feet on the desk of the Medicaid director for your state.

>> DRAKE EWBANK: Yes.

>> DANIEL FISHER: Stand on the desk.

My experience is it's good to have both inside and outside advocacy.

>> DRAKE EWBANK: Enlightened administrators have been responsible for most of the innovations that I have seen in the system over time I have been in it. So, you know, having...

>> DANIEL FISHER: There was one person who was... yeah, there was somebody named "Moore" in Oregon that seemed to play an important role early on.

>> DRAKE EWBANK: Michael Moore was the champion of this particular service within the Oregon health plan, and he's the one that set up the way the services run out of the mental health division, as well as he is helping ‑‑ he had a lot to do with the book that I think you ended up with. He had a vision for it.

>> DRAKE EWBANK: By the ‑‑

>> DANIEL FISHER: By the way there is a booklet that Oregon has put together. It's called "Recovery Through 20 Hours of PCA Services." And through the National Coalition. And you can email me, and I don't know where else it's available. If you email me I'll send anybody that would like a copy of this manual. It's quite exhaustive. It's over 100 pages. And it does detail a lot of these factors. I'll just make sure that I have my email address. How else is it available, Drake? I got it like 10 years ago. I can't‑‑

>> DRAKE EWBANK: It's archived with the state somewhere.

>> DANIEL FISHER: But I do have ‑‑ I have a copy of it, and I'm glad to share it with people. Just send me an email. Because I ‑‑ and, two, the national coalition, we would like to see more of these services present, and we will try to help promote them in other states. Maybe we could, you know, have consultation in some ways. Drake might be available for consulting other states. Is that a possibility?

>> DRAKE EWBANK: The one thing I would say about that manual is considering how outdated it is, the vision of how this works has been expanded by the state by rote.

There are a lot of things that they detail in there that don't really operate as conservatively as they did initially. The definitions of what can be done by a PCA has been expanded a little bit. And it's worth ‑‑

>> DANIEL FISHER: It would be good to have a new version.

Also a version that talked a little bit about Comagine. It's not in the original. It came out 2006. What is the name of the manual? Do you remember the name of the manual, Drake

>> DRAKE EWBANK: I can look.

>> DANIEL FISHER: Recovery through PCA is what I remember.

While Drake is looking that up, we have another question. I'm also in Vermont and would also like to know where we should start to implement PCA services.

I think it sounds like in Vermont you have a good foothold if you've got already a registry of PCAs for developmental disabilities. I wonder if the organization that has created that registry would be someplace to go to try to expand it to behavioral health. You think that might be possible, Drake?

>> DRAKE EWBANK: Can you repeat the question?

>> DANIEL FISHER: In Vermont they said that they already have a registry for PCAs for developmental disabilities. I wonder if it would be helpful for this person, if they want to get something going for behavioral health, it would be helpful for them to go to the particular organization that has created add registry for the disability PCAs, if that would be helpful if they go there.

>> DRAKE EWBANK: I would say only if they're managed by the same commission and entity, if they're regulated by the same people. Otherwise your friend makes apples with oranges, because not only do the waivers differ, the other things that would be required to implement something is going to be different. But you can ask certainly.

I see someone from Vermont. Someone else says that it's ARAS solutions that has created the registry.

I hear what you're saying, Drake, that it's a different type of service, because developmental disabilities, they have ‑‑

>> DRAKE EWBANK: Not so much a difference in services, a difference in the qualification of the client, what services that that ‑‑ like to get services from across programs is difficult. It's like the Medicare Medicaid gap there, places where there are simply big gaps.

>> DANIEL FISHER: It's good people are answering their own questions here, I like that.

We have just ten minutes left. Are there other questions that you might have?

Almost want to read out the question in Vermont. The question was: Where do I begin to set something like this up? And one answer to that is I talked with Sarah Landerville, at the Center for Independent Living or Kristy Murphy at the DD Commission. This is a very interesting point. And that is I think the role of Independent Living Centers in organizing PCAs for behavioral health, Drake, has that occurred at all? Has there been any connection between the Centers for Independent Living and the PCAs for mental health?

>> DRAKE EWBANK: No, again, because it's a different ‑‑ the independent living programs are funded in a much different way. So the only thing I know of that is like that where the Independent Living Center here in Eugene ended up with a peer' run drop‑in center. It was on a general grant and not funded by anything in particular.

>> DANIEL FISHER: In the charter for Independent Living Centers, they're supposed to provide services to people with mental health disabilities as well as other disabilities. And yet often they refer them to the mental health system. Whereas if they had PCAs that might be a way ‑‑ PCAs might be a way for them to reach out to the ‑‑ and support people with ‑‑ because my experience in independent living centers often do a lot of work with PCAs in this state at least for other disabilities.

Why couldn't they do them for behavioral health?

>> DRAKE EWBANK: You're asking the $64,000 question. There's a lot of disconnects like that.

>> DANIEL FISHER: That's why it doesn't respond comprehensively to people's needs rather than comprehensively to the way they're funded and authorized. That's a pretty common gap, definition of the gaps in the system. It's like the ‑‑

>> DANIEL FISHER: Here we go. Here is a question, I think it's one in the future I would like to have a webinar on, and how Independent Living Centers could provide this service. In Oregon, Senate bill 1606 is new, last year insure sures those with mental health distress, not official disability, they may have a support person in the hospital even in the pandemic. This includes in the ED, hospital, etc., and they are by law allowed at least three named support people, not at once, a PCA can be aware of this law in Oregon and bring printed information to the ED. Emergency department. People were denied this pandemic prior to this, and psychiatrists could not as easily see their home supports.

Are you familiar with this 1606? Senate Bill 1606. Ensures that those with disabilities, including mental health, they may have a support person in the hospital. Hmm...

Well, we're research that. It looks like an interesting one. Are there any other questions? I know that we had ‑‑ did we cover all of our ‑‑ case managers can be a response for quality assurance. Might say a word about that.

What does that mean?

>> DRAKE EWBANK: They haven't gotten that far. The program has never been developed enough that the quality assurance ‑‑ any kind of benchmark for quality assurance have ever been set up or surveyed. And it's also because all of the clients are individual employers.

They literally have to have every client doing a quality assessment.

Or ask all of the providers who are not organized and not in a central location about the quality of their care. So I think that's the explanation of that so far.

There's no central organizing piece. It's difficult to get comprehensive data.

>> DANIEL FISHER: Here is a summary, by the way, you know, you worked hard on the slides. Potential recovery based benefits of the PCA relationship when the PCA is a peer.

You know, PCA traditionally not necessarily have been peers, but a peer has a piece. PCA can have an additional ‑‑ some additional benefits.

Many of the benefits peers have, it also benefits to be a PCA, because within the clinical system it's often constraining more as a peer than working as a PCA. It might be a good starting point.

>> DRAKE EWBANK: Yeah, that would be an easy job and appropriate job for a peer to have, especially with something that they had ‑‑ some rapport, by lived experience.

Those are advantages in a PCA relationship. I wanted to speak to an announcement that just came up in the chat that we didn't make it physically through the slides, but we just covered in conversation, as well as points made almost everything that is in the slides. The slides are just an ordered documentation of everything that we have been talking about here.

>> DANIEL FISHER: I apologize too, because I was moving forward. But I do think we covered most of it.

Here is a slide showing my email and showing Drake's email. And showing SAMHSA's website and SAMHSA's phone number. This was funded by SAMHSA.

And thank you all very much for your time. This has been very enlightening. Drake, I want to thank you especially for sharing so much of your knowledge and your wisdom, and I daresay this is ‑‑ this program on PCAs for mental health has great promise. I was just talking to a SAMHSA official about this, and they said in the new era that we're into, with the possibility of increased funding for community supports, that PCAs for mental health could play an increasingly important role, and hopefully we will find a way to promote these in other states and use the example of Oregon, and promote them further in the state of Oregon itself. Do you have final words, Drake?

>> DRAKE EWBANK: I would like to say this is the tip of the iceberg. I mean, the benefits of this program are actually limited only by how scaled‑down it is.

The more resources you develop and the more expansions of the kinds of supports, the outcome is better, people will be better off and better served in the community and programs will actually be able to actually look at results, you know, outcomes as a real part of the system again. Which I think is important. That sounds sort of officious, but the proof is in the pudding. The proof is in the pudding, in that people that have meaningful relationships are able to establish themselves in the community in different ways and find ways to survive are way better off than just using the mental health system as their only support.

>> DANIEL FISHER: Thank you very much. Kelle, do you want to encourage the people that are still present, maybe they can get some feedback? I see some very lovely feedback, by the way. Thank you all very much for that feedback. A few of you that remain here could do this survey, it really would help for future ‑‑ in the future.

Thank you.

>> KELLE MASTEN: Thank you, everyone. I would like to thank everyone for joining today. Please take a few moments to fill out the evaluation for us, and I would like to thank SAMHSA again for allowing us to share this information with you today.

Enjoy the rest of your afternoon.