

# **The Coalition for Whole Person Supports**

## **By My Side Concept Meeting and Discussion – 11/24/25**

### **Meeting Summary and Transcript**

#### **Meeting Summary**

##### **Quick Recap**

The Coalition for Whole Person Supports presented a new model for service coordination focused on person-centered, holistic support for individuals with IDD, featuring a trusted navigation professional who provides flexible, conflict-free assistance. The discussion covered implementation details including training requirements, reimbursement structures, and measurement approaches for outcomes, with participants exploring challenges around system navigation and workforce continuity. The conversation ended with plans for a pilot program to test the model's effectiveness and upcoming webinars focused on workforce development and innovative support models.

##### **Coalition's Holistic Service Model Overview**

Courtney provided an overview of the Coalition for Whole Person Supports, explaining how it was formed and the process of developing recommendations. She introduced Mai Pham, who will present a conceptual idea that aligns with the coalition's three main theme areas: holistic services, individual control, and workforce support. The presentation will focus on how this model can address these areas and provide opportunities for the frontline workforce.

##### **Person-Centered IDD Service Coordination Model**

Mai presented a new model for service coordination for individuals with IDD, drawing from research and best practices globally. The proposed model emphasizes a person-centered, holistic approach, with a trusted navigation professional chosen by the individual. This professional would be trained in various service sectors and sectors, offering flexible, conflict-free support. Mai outlined the potential benefits, including improved access to services, reduced stress for families, and a market-based model that allows individuals to choose their support. The next steps involve developing a training curriculum and piloting the model, with the goal of making it accessible to all individuals with IDD.

##### **Care Navigation Payment Model Discussion**

The group discussed a care navigation model that emphasizes person-centered care and gives individuals choice in selecting their support team. Mai explained that payment for care navigators would be linked to outcomes, potentially through retrospective bonuses or adjusted fees, and mentioned ongoing work to identify relevant measures for healthcare and HCBS. Diane Marrone inquired about the reimbursement structure and outcomes

expectations, prompting Mai to describe various approaches to measuring success, including person-reported outcomes and goal attainment scaling.

### **Disability Support Pilot Program Review**

The meeting focused on a pilot program aimed at improving support systems for individuals with disabilities. Mai discussed the need for standardized training and certification for case managers to ensure competence across various sectors, emphasizing the importance of a pilot program that includes diverse participants to test the model's effectiveness. Participants explored challenges such as navigating complex systems, workforce continuity, and the limitations of current infrastructure, with Lucille highlighting the need for broader systemic changes. Ryan announced upcoming webinars in December and January featuring experts to discuss workforce development and innovative support models.

### **Meeting Transcript**

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Courtney Burke: Hello, everyone. Folks are still joining, so we're gonna give it just a minute before we get started.

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Courtney Burke: Alright, looking like we have a bit of a critical mass here, so I think I'm at least gonna get.

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Courtney Burke: the kickoff going to give an overview, um, and a catch-up, because many of you we haven't seen for a couple months, and wanted to level set before we get into today's.

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Courtney Burke: presentation topic, and before I...

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Courtney Burke: introduce our speaker. So, um, so let me start there. So I'm Courtney Burke. I work for Saks Policy Group.

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Courtney Burke: We are hosting this webinar today, um, at the request of members of the Coalition for Whole Person Supports.

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Courtney Burke: Many of the people I can see who are on the Zoom today have been part of that process and have had input into that process along the way. And just as a general reminder of how that process worked, um, initially, it's... the whole genesis of the coalition actually started with a couple providers.

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Courtney Burke: that SACS policy works for and with.

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Courtney Burke: Who said to us, we're concerned about the sustainability of the system, and we don't think it's holistic enough in its delivery.

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Courtney Burke: And they sent out a call letter for, um, interest in the topic.

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Courtney Burke: They then said, you know, there's really not, um, we want to see more involvement from families and individuals and more input from them in this process.

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Courtney Burke: So we then developed 3 groups for that process.

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Courtney Burke: Um, and input to happen.

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Courtney Burke: First was the advisory board, then the input group, then the steering committee.

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Courtney Burke: What we asked the advisory board to do was to.

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Courtney Burke: Look at some of the models that we had done webinars about.

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Courtney Burke: Late last year, uh, and into the beginning of this year, and they gave their thoughts on what's working, what do we like, what do we not like.

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Courtney Burke: And then we asked the input group to build on that, add additional recommendations, and they had great suggestions, including that we needed to get input from direct support professionals and care managers, so we did a couple sessions with.

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Courtney Burke: Those groups to get additional recommendations.

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Courtney Burke: We then brought the 70 or so recommendations to the steering group and asked them to try to help focus what the recommendation should really be about, because.

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Courtney Burke: 70 recommendations is a lot. It's not necessarily that practical to implement them.

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Courtney Burke: So, the steering group came up with criteria to rank the recommendations.

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Courtney Burke: Um, they looked at...

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Courtney Burke: Things like, how feasible is this?

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Courtney Burke: How in line is it with the goal of whole person Supports?

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Courtney Burke: how in line is it with the state's 507 plan? Is it going to have a big impact?

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Courtney Burke: And based on that ranking, they came up with sort of a top 10 list.

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Courtney Burke: We put a little bit of meat on that top 10 to make those items more actionable.

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Courtney Burke: And then we said, you know what? A lot of these really overlap, and there seem to be.

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Courtney Burke: Three general theme areas in those top 10 recommendations.

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Courtney Burke: Those three theme areas were, first of all, whole person, so not a surprise. In other words, the recommendation would help with making services more holistic.

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Courtney Burke: The second grouping, it was hard to give it a label, but it was a lot about giving people more control, so there was...

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Courtney Burke: Some of the recommendations were very focused on self-direction.

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Courtney Burke: Uh, or person-centered services.

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Courtney Burke: And the third area focused on workforce and supporting the frontline workforce.

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Courtney Burke: What happened at that point was this... the steering group asked us at Saks Policy if.

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Courtney Burke: on behalf of the Coalition, we could continue to do educational forums in those three theme areas.

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Courtney Burke: So today is the first day that we are launching, um, some webinars.

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Courtney Burke: on the three theme areas, and I'm very excited, and I'll introduce our speaker in just one minute.

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Courtney Burke: Before I do that, I just wanted to...

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Courtney Burke: Show people and remind folks that if you want to see the recommendations or, um, any of the materials.

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Courtney Burke: That the Whole Person Coalition has developed over the course of time.

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Courtney Burke: We do have a website, and I know many of you have been to that website.

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Courtney Burke: Um, and have used it before. So let me, um, pull it up to give you the quick 101 on where things are.

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Courtney Burke: Uh, within that website, and I'll do that by sharing my screen briefly. So this is the home page.

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Courtney Burke: And one of the best places to go, um, on the homepage.

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Courtney Burke: is to go under the materials.

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Courtney Burke: And, let's see, here it is. Uh, meetings and events, and materials and information.

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Courtney Burke: So, the materials and information page, let me click on that.

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Courtney Burke: That's where we have the top 10 recommendations with examples of things that could be done in the area.

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Courtney Burke: This has the full list of recommendations that came from.

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Courtney Burke: The advisory group, the input group.

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Courtney Burke: Um, and then we have a lot of other resources there that have been developed over time, which are different presentations that have been done. So I just wanted to make sure that.

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Courtney Burke: As a reminder that people can find.

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Courtney Burke: Uh, these materials on the website there.

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Courtney Burke: And it's HTTPS...

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Courtney Burke: With a colon, two backslash.

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Courtney Burke: Whole Person Supports, all one word, dot org.

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Courtney Burke: Because if you just Google whole Person Supports, you're going to get a whole bunch of different things that are not necessarily.

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Courtney Burke: the website. Um, so thanks for that, allowing me to go through, sort of, the history here and the reminders.

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Courtney Burke: With that said, I do want to reserve.

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Courtney Burke: time after the presentation for some feedback and discussion, and I also want to reserve a minute or two for us to let you know about the upcoming webinars that we have.

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Courtney Burke: Scheduled that are open to everyone.

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Courtney Burke: With each one of the webinars, we're going to be recording it and putting it on the Whole Person website, on the meetings page, so that anybody can view it at any point in time. So if you know folks who are missing today.

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Courtney Burke: They still will be able to access it in the future.

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Courtney Burke: All right, with all of that said, it is my incredible pleasure to introduce Mai Pham, who is the leader of.

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Courtney Burke: Uh, the Institute for Exceptional Care.

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Courtney Burke: Many of you know my Pham, and I know Bj Stasio.

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Courtney Burke: Has worked with my Pham, and I know Bj's on today as well. I think he's going to chime in after the presentation, but many of you know her and the great work that they have done.

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Courtney Burke: And it's interesting how this came about. Admittedly, this was sort of my choice to invite them to present, because I was familiar with their work.

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Courtney Burke: And I was trying to think about who would be a great resource on whole-person supports.

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Courtney Burke: So I reached out to my fam at IEC.

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Courtney Burke: And she told me, actually, I've been working on this conceptual idea.

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Courtney Burke: And it was, um, not just about whole person. I think the model really spans across all three theme areas that I mentioned.

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Courtney Burke: It focuses on how to make services more holistic.

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Courtney Burke: It gives a lot more control to individuals and families.

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Courtney Burke: And it promotes and provides opportunities for the frontline workforce. So I was like, oh my gosh, you're our first guest, and you're already covering all three theme areas.

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Courtney Burke: with your idea. So, um, so without further ado, my Pham, I'm going to turn it over to you, and let me know if you have any trouble sharing screen, because I can pull up the PowerPoints if you have any problems.

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Mai Pham: Thanks, Courtney. Um, let me just get the share up now.

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Mai Pham: Thanks. And, uh, for those of you not as familiar with Institute for Exceptional Care, IEC is a national nonprofit. Our mission is to make healthcare better and safer for people with IDD.

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Mai Pham: And we do that, um.

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Mai Pham: Uh, having come together as a group of.

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Mai Pham: professionals in healthcare, so clinical experience, policy experience, management experience in healthcare, but also with the lived experience. Some of us have IDD, some of us support family members with IDD.

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Mai Pham: And, um, literally how IAC does our work is we are the bridge. We bring together actual community members.

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Mai Pham: adults with ID, self-advocates, and family members, and then we put them in the same room as really important healthcare decision makers, and we facilitate.

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Mai Pham: the development of solutions together. So, what I'm sharing with you today is, um, some conceptual work that we did a little while ago, because we are haunted, as I know many of you are, about.

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Mai Pham: Why, um, we still live in a world where.

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Mai Pham: One has to get a PhD in social work in order to be able to navigate services, and even then, you're not guaranteed of success.

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Mai Pham: Um, and so the idea here was to try to understand what are the models, what are the options out there.

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Mai Pham: And which ones work best. Um, and if nothing works well.

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Mai Pham: What can we invent that might work better?

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Mai Pham: So, we worked with, um, a consulting group called Health Management Associates.

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Mai Pham: And they interviewed 28 stakeholders, uh, from different walks of life.

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Mai Pham: They also did a literature review.

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Mai Pham: Um, and...

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Mai Pham: Did that literature review looking for models of service coordination.

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Mai Pham: They wanted to understand how care coordination is defined, if it's defined, what existing frameworks there are, what gets in the way.

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Mai Pham: And, uh, and how...

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Mai Pham: People who need to receive the services, what their role is in each model.

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Mai Pham: So, what we, um... what they found, unsurprisingly, was that while there are lots of models of service coordination out there.

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Mai Pham: Very few of them.

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Mai Pham: Work across different.

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Mai Pham: types of services. So very few of them cross sectors, like clinical services.

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Mai Pham: Housing, vocational, education, social, etc.

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Mai Pham: Um, so that was one initial finding.

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Mai Pham: So, we all know about the IDD population, I won't belabor that, but.

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Mai Pham: you know, a lot of the reasons why people with IDD experience worse health and life outcomes.

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Mai Pham: Is that they have a lot of difficulty accessing, accessing holistic services.

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Mai Pham: From a standpoint of someone who understands who they are individually, and what their.

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Mai Pham: Their specific goals and needs are, and who can help smooth the way and help advocate for them.

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Mai Pham: Um, when we talk about sectors, these are just some of the major ones, right? Financial support, educational support, employment, housing, healthcare.

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Mai Pham: I'm sure you can add to this, but the point is that even when there are service coordination models out there, they tend to live in one sector or another sector, but they don't really support services and making things mesh together across different sectors.

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Mai Pham: It's also, frankly, a lot of confusion around what coordination means. So even the frameworks that are out there, most of them don't even formally define what they mean by coordination.

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Mai Pham: Um, so we're gonna propose a definition of coordination.

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Mai Pham: Um, and one way to think of it is that it is a model.

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Mai Pham: of managing and arranging services that meets the holistic life needs of people with IDD.

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Mai Pham: So that gets to your first priority.

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Mai Pham: Um, and that it does this across diverse care and service systems and structures to share resources and information, to collaborate.

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Mai Pham: And to give people with more control... people with lived experience more control.

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Mai Pham: Um, but doing it in...

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Mai Pham: A setting of collaboration across different sectors.

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Mai Pham: So, sometimes when people say coordination... there are different terms that people use, so I just want to clarify that we considered all of these, okay? So, care coordination is, you know, organizing, um, service activities and sharing information across everyone who's involved in providing services to achieve safer and more effective care.

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Mai Pham: That's healthcare coordination.

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Mai Pham: There's healthcare coordination standards, especially for children and youth with special healthcare needs.

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Mai Pham: That, um, define care coordination as patient and family-centered.

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Mai Pham: That is driven by formal assessments of needs, that is team-based.

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Mai Pham: With activities that are really designed to meet the needs of children and youth.

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Mai Pham: So that's another way to look at it.

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Mai Pham: Case management is another term we throw around, and that is a process that accesses plans.

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Mai Pham: implements, coordinates, monitors, and evaluates options for services to meet a client's health and human service needs. So.

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Mai Pham: A health plan may have a case management program.

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Mai Pham: A community-based case management program is all of those things, um, and really, it's just the mirror of that.

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Mai Pham: Just not based in a health plan, but maybe in a community, maybe at a community clinic.

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Mai Pham: Um, or with an HCBS agency.

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Mai Pham: And then there's Medicaid home and community-based services case management.

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Mai Pham: And that is helping participants gain access to specific waiver or other state plan services.

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Mai Pham: as well as medical, social, and other services. So that one really does try to cross sectors, but it is anchored in Medicaid and in HCBS.

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Mai Pham: So, some of the problems with having won so many different.

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Mai Pham: Models and approaches, and also so many different definitions.

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Mai Pham: And different sponsors, if you will.

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Mai Pham: of these coordination programs is that the system is fragmented.

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Mai Pham: Um, which means, again, you need that PhD in social work.

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Mai Pham: to find your way through it. There's not great information sharing. The information systems don't mesh.

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Mai Pham: The definitions in those information systems don't mesh.

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Mai Pham: And people just have no incentive to share with one another. Schools have no incentive to share with a clinician's office, or vice versa.

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Mai Pham: Um, what ends up happening, and I speak from experience, is that the family and the self-advocate end up being their own coordinators.

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Mai Pham: Um, and then we're... we shouldn't be surprised that the bad outcomes follow, because it just puts undue stress on something that professionals should be taking care of.

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Mai Pham: What we, um, found in terms of what exists out there is that there's certainly coordination services provided by, say, a hospital system.

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Mai Pham: Or clinics, large clinics.

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Mai Pham: Managed Care Insurance Comp...

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Mai Pham: plans. We'll provide case management.

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Mai Pham: There's some specific models designed for high-risk populations.

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Mai Pham: For example, for transplant patients, or for children and youth with special healthcare needs.

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Mai Pham: Um, Medicaid can have HCBS case management, as we talked about. There are also Medicaid health home models.

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Mai Pham: Uh, that are delivered through clinical teams.

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Mai Pham: And then there's non-health-related coordination or case management.

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Mai Pham: However, none of these really get to that holistic approach.

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Mai Pham: Um, never mind one that puts the person with the service needs at the center of decision making.

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Mai Pham: Um, so I won't go through this in detail. You are welcome to the slides afterwards, but I will just note that having reviewed all of these existing models.

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Mai Pham: Honestly, where there was nothing in the U.S. we found that met what our stakeholders told us were really important criteria. We had to go all the way to New Zealand.

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Mai Pham: And that's the last one that you see down there. It's this notion of local area coordination. Now, it works.

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Mai Pham: differently in places like New Zealand or the United Kingdom, because there, everyone is assigned a primary care clinic.

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Mai Pham: Right, and so you know geographically who you're responsible for, and that's not the case here.

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Mai Pham: But what we are trying to mimic is.

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Mai Pham: How, um, small the caseloads are.

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Mai Pham: How important that one-on-one relationship is between the navigation expert and the person who needs the services and their families.

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Mai Pham: Um, and the fact that this has generated positive outcomes.

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Mai Pham: So, what are those criteria? What are we trying to... if we're going to invent something, what are the features of that thing we want to invent?

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Mai Pham: Well, we want it to be...

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Mai Pham: Um, invested in a coordinator or a navigation support person who is trusted.

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Mai Pham: Okay, so who does...

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Mai Pham: a person with IDD trust.

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Mai Pham: That should be up to them to decide.

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Mai Pham: Which implies that they should be able to choose the person who's gonna help them navigate.

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Mai Pham: Okay. A single point of contact.

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Mai Pham: So, that one person is their entry point, it's the only relationship they have to worry about, and that person manages all the other relationships behind the scenes.

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Mai Pham: Small caseload and flexibility, and, you know, what we mean by small is debatable. I think that's up for discussion, but we were imagining no more than 40 to 60, um, cases per navigator.

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Mai Pham: Someone who can take a person-centered approach, so it's not a one-size-fits-all checklist, it's really understanding what that person wants, what they need, thinking

about them holistically, and being flexible, both in how you engage them and what you engage them with.

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Mai Pham: When we say neutral coordination, what we mean is, right now.

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Mai Pham: care navigators, case managers, coordinators, they are all employed by someone. They are all employed.

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Mai Pham: They might be employed by a hospital system, by a health plan, by a Medicaid agency, um, etc.

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Mai Pham: Which means that no matter how well-intentioned they are, they have a conflict of interest.

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Mai Pham: They have to balance the interests of those of their employer.

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Mai Pham: versus the interest of their clients. What we want is a navigation person who does not have those conflicts of interest.

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Mai Pham: We also want a model that anyone can access, right? So right now.

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Mai Pham: you know, you're lucky if you have Medicaid if you're in an area that has Medicaid health homes.

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Mai Pham: Or you're lucky if you're in the right clinic, and they have a coordinator.

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Mai Pham: You shouldn't have to be lucky.

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Mai Pham: You should be able to have an option.

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Mai Pham: For really effective, holistic navigation support, regardless of your life circumstances.

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Mai Pham: Um, we certainly want someone who is fluent enough in the language and the systems across these different service sectors, like vocational, educational, healthcare, HCBS.

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Mai Pham: to help with that information sharing, right? Because that's a lot of what family coordinators do right now, is we hold all the bits of paper and all the notes and all the little pearls we've learned about our loved one, um...

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Mai Pham: Or self-advocates have to walk around with that themselves, and.

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Mai Pham: Having a professional take responsibility for that would be awesome.

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Mai Pham: And then, uh, not least, having a model that we can measure success for.

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Mai Pham: So, um...

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Mai Pham: One other thing I'll just... this is... this is a little bit overlapping with the slide I just showed, but.

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Mai Pham: One other thing to point out is that.

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Mai Pham: If you can set up a system.

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Mai Pham: Where the navigation support person.

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Mai Pham: is by my side.

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Mai Pham: My whole life.

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Mai Pham: or as long as both I and they are alive.

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Mai Pham: Um, that would just make for such a very different relationship.

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Mai Pham: Not just in the interactions and the quality of those interactions, but also in the wisdom that that navigator develops about that person.

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Mai Pham: And how they can apply that in navigating services and advocating for that person.

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Mai Pham: It also means a whole lot less work and stress.

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Mai Pham: for the person with IDD and the family, because you don't have to... let's say, you know, someone switches jobs.

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Mai Pham: Um, you don't have to suddenly lose your navigation support person.

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Mai Pham: And now you have to start all over with a total stranger who doesn't know you at all. So, having this service be portable across life changes.

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Mai Pham: Um, is really, really important.

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Mai Pham: Um, so, this is just a summary of what we're trying to look for.

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Mai Pham: A system that's person-centered, that takes context and environment into account.

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Mai Pham: That is accessible, no matter your life circumstances, is flexible, it's relationship-based, it's free of conflicts of interest.

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Mai Pham: It's local. Now, that is one thing that conflicts with the portability concept.

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Mai Pham: You know, to really be wise about navigating services, you need to understand what's available in the community.

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Mai Pham: And so, um, it's hard for someone in California to figure out what the best way is to navigate services, say, uh, in the Bronx. Um, so we acknowledge that.

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Mai Pham: Right? Um...

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Mai Pham: And certainly this model needs to adhere to disability values, like prioritizing community integration.

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Mai Pham: And honoring self-determination.

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Mai Pham: And then, again, that holistic view across domains.

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Mai Pham: So, um...

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Mai Pham: Again, just a lot more detail here, but underscoring that.

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Mai Pham: If the first decision is who my service navigation support person will be.

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Mai Pham: And the person with IDD can make that decision.

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Mai Pham: Uh, with or without their family's help.

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Mai Pham: That really sets the tone.

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Mai Pham: For placing their perspective at the center of the model.

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Mai Pham: Okay, so, um...

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Mai Pham: Here it is. Here's the buy-my-side model, at least the skeleton of it.

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Mai Pham: Right? What we're talking about is.

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Mai Pham: Having a professional.

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Mai Pham: Who could, say, begin their career as a direct support person, or a social worker, or a nurse.

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Mai Pham: But someone who, um...

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Mai Pham: gets training.

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Mai Pham: in IDD.

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Mai Pham: as well as in the services and systems of the different sectors, right? So, who is fluent in healthcare, is fluent in HCBS, is fluent in housing, is fluent in education?

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Mai Pham: And they go through a training process that is rigorous and standardized, so that we know if you got to the other end of that, you are really prepared.

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Mai Pham: Um, and then they, when they finish this training.

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Mai Pham: They can hang out a shingle, as we say, and take on.

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Mai Pham: clients. So they would have to essentially compete for clients.

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Mai Pham: Um, and we'll talk about what this looks like in the real world, but the point is.

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Mai Pham: It's the person with IDD who chooses them, right? Just as you would go choose your therapist, or your dentist.

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Mai Pham: Um, or your car repair shop. You're gonna be able to choose from a range of professionals, qualified professionals, who your navigator support person will be.

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Mai Pham: And then that professional can bill for their services.

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Mai Pham: They can bill any number of sources. They can bill the family and the person with IDD, they can bill an insurer.

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Mai Pham: They can bill the state.

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Mai Pham: Uh, whether that's the, um, OPWDD or Medicaid.

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Mai Pham: Um, if they are employed, or if they're, you know, if they're dependent of someone who's employed, that employer could even offer to cover this fee as a wellness benefit.

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Mai Pham: Right, so the compensation can come from multiple sources.

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Mai Pham: Just as a dentist can get compensation for multiple sources, right?

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Mai Pham: And then there's, um...

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Mai Pham: an accountability mechanism, right? Somebody is measuring the outcomes of.

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Mai Pham: Of navigation for those clients.

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Mai Pham: So, I just want to point out.

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Mai Pham: And really hope this is the start of a conversation about.

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Mai Pham: What the, um, advantages of this type of approach could be.

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Mai Pham: Um, first of all.

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Mai Pham: Having formalized training and a credential that is offered at the end of that training.

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Mai Pham: Um, means that this could be a really rich professional development path.

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Mai Pham: For frontline professionals, especially those who already have field experience under their belt from having done direct service.

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Mai Pham: Um, and, uh, and...

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Mai Pham: there's a lot of flexibility, right? Just as there's flexibility, if you are a newly minted physician, you can choose to have a solo practice, you can, um...

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Mai Pham: become a partner in a small group practice. You can work for a hospital system and be an employee.

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Mai Pham: And so these navigation professionals.

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Mai Pham: could similarly have those kinds of options. So, if they're working within an HCBS agency now, for example, that HCC can decide, you know what, we want some of our... our...

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Mai Pham: staff to actually offer this service and get that certification. And they still are competing for clients, but it's now, you know, a different caseload, a different set of responsibilities.

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Mai Pham: And then that agency can serve as what, you know, in healthcare we would call a management service organization, which is kind of like your back office.

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Mai Pham: So the professional doesn't have to worry about how to bill, how to, you know, set up phone lines or things like that. The MSO takes care of all of that. The professional just does the work, and then they get their, you know, their payment.

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Mai Pham: Um...

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Mai Pham: this creates an option, right? It's... this is not about replacing current options. If people like their current options.

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Mai Pham: We don't want to disrupt that, but it creates a new option for people, and especially for people who can't access formal.

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Mai Pham: models of coordination support right now. So if you're not in OPWDD, you're not getting an HCBS case manager right now. This creates an option for you there. Um, and a lot of children with IDD don't have any formal options either.

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Mai Pham: Um, and then, um, you know, essentially, this is a market-based model. This is really about how that relationship forms.

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Mai Pham: Um, how rewarding that is.

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Mai Pham: for the person with IDD as the client.

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Mai Pham: And for the navigation support person as the provider, um, and that, you know, people get to choose.

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Mai Pham: Um, because that relationship is really the driver of good decision making.

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Mai Pham: So, as we think about, you know, well, how would this model become real?

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Mai Pham: Um, and we're just starting to brainstorm that. We would love to work with.

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Mai Pham: people on the ground, um, and move this forward. But, you know, at a high level, what it looks like is we'd first want to develop the training process.

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Mai Pham: So what is the content that these professionals would need to learn? A lot of it already exists. It's a matter of pulling it together, um, and developing that curriculum.

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Mai Pham: Uh, and then we want to pilot it, right? So.

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Mai Pham: there are different ways of piloting it. Could a state sponsor a pilot? Absolutely.

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Mai Pham: But since this is a model that we want to be accessible to people, even people who are not receiving state benefits, we could also imagine a pilot that's just kind of out there in the private sector, right? Where maybe a grant covers the fees for the service, and anyone with IDD can choose to participate.

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Mai Pham: Um, and it doesn't necessarily require state sponsorship.

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Mai Pham: And then, if that pilot is successful and we can work through the kinks, then we start shopping this model to, um, other entities who could pay for it and make it sustainable in the long term, which would be insurance companies and state agencies, um, and employers, and of course, individual families and self-advocates.

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Mai Pham: So, let me stop there. I hope that leaves us plenty of time for...

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Mai Pham: questions and discussion, and I would also love to invite Bjay and other.

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Mai Pham: Other self-advocates on the call to chime in with your thoughts on the model.

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Courtney Burke: Thank you, my Pham, and I'm going to defer to Bjay and others.

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Mai Pham: And, uh...

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Courtney Burke: To have the first comments and questions.

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Mai Pham: I'm gonna stop sharing. I'm happy to show the slides again if you need to refer to something, but...

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Bj Stasio: Well, Mai is always a good job.

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Bj Stasio: You forgot your shaker to wake people up, but that's good.

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Bj Stasio: You know, and one thing I like about it, as I've always told you, Mai and everybody else.

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Bj Stasio: Who knows what makes me tick? The more person-centered things...

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Bj Stasio: are, the better the system will be, so...

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Bj Stasio: It's good to know that all the conversation we've had as a group, and I've had with you separately.

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Bj Stasio: I feel my voice is heard with IEC, and my voice is heard with this group, so that's what makes it good, and I know this group.

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Bj Stasio: Values what self-advocates say, so...

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Bj Stasio: I'm just glad to be a part of both worlds, and hopefully someday everything we talked about.

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Bj Stasio: Comes to be, but with... with change takes a lot of convincing and a lot of...

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Bj Stasio: A lot of hand-holding or hand slapping in some cases.

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Bj Stasio: To get people to listen, but...

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Bj Stasio: I guess that's what we have to do.

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Courtney Burke: Hm.

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Mai Pham: Thanks, PJ.

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Courtney Burke: Yeah, and I'll just comment, um, the reason that I liked this model so much was that I did feel that it touched on all of the priority areas, the themes that came out of the whole person.

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Courtney Burke: Work, and first being that it is supposed to be more holistic in how the care is provided, because you have that person with you by your side.

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Courtney Burke: Along with all of the systems that they might be encountering.

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Courtney Burke: It also gives the person the choice to choose who they're working with.

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Courtney Burke: Which is... which is different. It... and it provides opportunities for direct support professionals and others who might... might be chosen.

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Courtney Burke: Um, to advance in their career.

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Courtney Burke: And to have more independence, to hang their own shingle, as you phrased it. So, I'm going to facilitate. I see that there are some hands up, and I'm going to start with.

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Courtney Burke: Uh, Diane Marrone, who...

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Courtney Burke: Diane?

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Diane Marrone: Thanks, Mai. This is... this is great. I love so many things about the model.

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Diane Marrone: Um, I just had a question when it came to, um, you know, I think what I saw on one of the slides was that what was proposed was.

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Diane Marrone: You know, sort of a per-year.

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Diane Marrone: payment structure or something like that to whomever the care navigator would be, and I love the idea about having.

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Diane Marrone: Um, you know, the assignment of this coordinator being driven by the person themselves.

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Diane Marrone: Would you see there being anything that would be connected to, you know, anything within the reimbursement being connected to any particular outcomes that are expected.

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Diane Marrone: So that there's some objective, you know.

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Diane Marrone: Right, I think what we get caught up in, you know, and I could say, you know, I lead care management for a CCO Health Home that also right now includes, um.

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Diane Marrone: any of the individuals that are still enrolled in the FIDA IDD plan. And those are two completely different payment structures, right? In one, it's a complete fee-for-service model from care management, and the other, it's not at all, right? It's really a per-member, per month that's based on, you know, general outcomes.

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Diane Marrone: Um, and I think it's always a struggle to figure out, like, what is...

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Diane Marrone: what are we... what are we reimbursing people to do? So, have you given any thought to how that might work in this model?

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Mai Pham: Yeah, so, uh, I'm a payment gal.

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Mai Pham: Um, so... so yes, um, Bjay and Marco and I just got back from a large multi-stakeholder meeting where we were just talking about what outcomes are most important to people with IDD.

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Mai Pham: And in the healthcare space, uh, well, actually, it cuts across healthcare and HCBS, because it's really about life outcomes.

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Mai Pham: Um, I think that's a great starting point.

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Mai Pham: to start with, that are more healthcare-anchored, but are more general than just healthcare. Um, but...

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Mai Pham: there were also a lot of gaps, a lot of priorities went where the measures don't currently exist, and I think there are different ways to fill those gaps. So, there are, uh, what I would call, uh, person-reported outcome measures, right? Um, so, which might be, might be related to employment.

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Mai Pham: It might be related to housing. It might be related to a part of their health.

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Mai Pham: Um, you can find different measures of that. There's also kind of a global goal, goal-oriented measure, um.

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Mai Pham: Where it doesn't matter what the goal is.

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Mai Pham: There's a scientific way to scale it.

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Mai Pham: So that you can... you can compare, okay, how is this navigator... navigator's clients doing?

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Mai Pham: relative to their goals versus how is this navigator's clients doing relative to their goals. Um, we call that goal attainment scaling.

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Mai Pham: Um, and yes, I do, I do think it's important to link payment.

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Mai Pham: to... to link incentives to those outcomes. So you might have to do that retrospectively, you know, based on... maybe that's a bonus system, maybe that's changing the fee the next year, but absolutely, I believe in that.

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Diane Marrone: Thanks, that's great.

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Courtney Burke: Great question. Great question. Thanks, Diane. Marco, I saw you have your hand up.

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Courtney Burke: You're on mute.

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Marco Damiani, AHRC NYC: Okay, I'm a good Zoom guy. Um, great to see you, man. Long time no see. You too, BJ. Um, so...

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Marco Damiani, AHRC NYC: I love this for so many reasons. Um, I think the complication here.

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Marco Damiani, AHRC NYC: it's not the model, it's how you pay for it. We've been talking about that a little bit already. Um, and I think it stitches nicely to what you just said.

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Marco Damiani, AHRC NYC: Mai Bout, looking at, um.

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Marco Damiani, AHRC NYC: Ideally, updating national standards or other... other existing standards to.

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Marco Damiani, AHRC NYC: assess the impact on the person's life that align with their goals, their health status, and so on. And this type of position.

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Marco Damiani, AHRC NYC: is a bridge, it is a poke, it is a security blanket in some ways to help those things actually happen the way that they should.

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Marco Damiani, AHRC NYC: you know, we're in New York, I know each state is different, you probably know other states better than we do to some extent, but...

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Marco Damiani, AHRC NYC: Um, it seems to me that the real challenge here is incremental change.

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Marco Damiani, AHRC NYC: that... I'm not sure this is a big bank solution, maybe it is in certain cases, but we know right now that.

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Marco Damiani, AHRC NYC: Well-off families do this already.

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Marco Damiani, AHRC NYC: They pay a social worker, they pay somebody else to be their own private.

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Marco Damiani, AHRC NYC: Case manager, while you also have, like, 5 other case managers for other parts of the system and so on.

00:50:08.000 --> 00:50:10.000

Mai Pham: Mhm.

00:50:13.000 --> 00:50:18.000

Marco Damiani, AHRC NYC: And I guess the question kind of buried in here is, have you thought about.

00:50:18.000 --> 00:50:22.000

Marco Damiani, AHRC NYC: an incremental approach to this, and have you thought about.

00:50:23.000 --> 00:50:34.000

Marco Damiani, AHRC NYC: a state or two states where you think it's most likely to actually grab, because I'm thinking that it is different across states. We're not a managed care state

right now in New York. That could be an upside and a downside. Just wondering about your thoughts on implementation.

00:50:35.000 --> 00:50:37.000

Mai Pham: Yeah, so, if I were queen.

00:50:37.000 --> 00:50:51.000

Mai Pham: Um, and I'm not... but if I were Queen, and I could just direct a foundation to fund, um, a pilot, you know, let's say we've developed the curriculum already, right, and we've got the training, um, model.

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Mai Pham: I... I would...

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Mai Pham: Structure a pilot that.

00:50:56.000 --> 00:51:01.000

Mai Pham: Had both, um, people who could afford to pay for it themselves.

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Mai Pham: The grant will pay for it, but you want people who would... who are already trying to purchase this in the marketplace.

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Mai Pham: But it's not quite the same, right? Because...

00:51:10.000 --> 00:51:13.000

Mai Pham: There is no standardized training right now in the marketplace.

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Mai Pham: So it's a total crapshoot if you go out and look for someone, right? You don't know, really, what you're getting.

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Mai Pham: If there was formalized training and a certification program.

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Mai Pham: you'd know what you were... you'd have a better idea of what you were getting, and you could hold that person more accountable, right? So that's point one.

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Mai Pham: But I would make sure that that grant covers and allows for participation by people living in a diverse set of circumstances.

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Mai Pham: So, that it includes people with private insurance, it includes people in straight Medicaid, it includes people getting HCBS waiver services.

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Mai Pham: Um, and it includes, you know, children and adults, although I might, I might sway a little bit there, one way or the other, just to simplify things.

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Mai Pham: Um, because what you want to test first is the safety and the effectiveness of a model.

00:52:05.000 --> 00:52:12.000

Mai Pham: Right, sorry for my FDA view coming in, but you first want to make sure that it's viable.

00:52:12.000 --> 00:52:19.000

Mai Pham: Um, and then you say, well, you know, really all that's standing in the way of scaling here are payment mechanisms.

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Mai Pham: I think you want a diverse population, because after the pilot, you want to be able to take those results.

00:52:26.000 --> 00:52:31.000

Mai Pham: Let's hope they're positive, and go to each of those potential funders.

00:52:31.000 --> 00:52:34.000

Mai Pham: Right? Each of those potential financiers.

00:52:34.000 --> 00:52:42.000

Mai Pham: Um, and say, hey, we had people who were in commercial insurance. Hey, we had people who were in Medicaid fee-for-service. Hey, we had people.

00:52:42.000 --> 00:52:45.000

Mai Pham: In waiver services and out of waiver services.

00:52:45.000 --> 00:52:47.000

Mai Pham: And it worked for everybody.

00:52:47.000 --> 00:52:50.000

Mai Pham: Um, that's how I would do it.

00:52:50.000 --> 00:52:52.000

Marco Damiani, AHRC NYC: Great points, thanks.

00:52:53.000 --> 00:52:58.000

Courtney Burke: All right, do we have other questions? Those are... those were two really great ones.

00:53:00.000 --> 00:53:02.000

Courtney Burke: Yes. Uh...

00:53:02.000 --> 00:53:05.000

Courtney Burke: Diane Fraser-Smith, make sure to take yourself off mute.

00:53:05.000 --> 00:53:09.000

Diane Frazier-Smith: Yes, I just want to ask a question, because it...

00:53:09.000 --> 00:53:12.000

Diane Frazier-Smith: Your, your pilot seems so, uh...

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Diane Frazier-Smith: Familiar with, um...

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Diane Frazier-Smith: Uh, a person that is, uh, getting self-direction.

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Diane Frazier-Smith: Am I wrong, or...

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Diane Frazier-Smith: Uh, is this pilot.

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Mai Pham: So...

00:53:28.000 --> 00:53:32.000

Diane Frazier-Smith: Is... is there some similarities?

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Diane Frazier-Smith: To this health direction.

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Diane Frazier-Smith: and your pilot.

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Mai Pham: Well, the main similarity is that.

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Mai Pham: The person has more control in self-direction.

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Mai Pham: And we are also trying to give them more control.

00:53:48.000 --> 00:53:52.000

Mai Pham: I think what's different is that the person in self-direction right now.

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Mai Pham: Is also facing a crapshoot when they go out looking for help.

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Mai Pham: They don't know who's been trained right.

00:53:59.000 --> 00:54:06.000

Mai Pham: Right? And they're still doing a lot of the work of figuring out what they need, how to get it, etc.

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Mai Pham: Um, this takes more of that burden off of them.

00:54:10.000 --> 00:54:16.000

Mai Pham: And it labels a professional as having gotten the certification, having gotten the training.

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Mai Pham: So you don't have to guess. You don't have to just ask yourself, do I believe this person when they say that they have experience working with schools, or they have experience working with housing agencies?

00:54:28.000 --> 00:54:35.000

Mai Pham: you know, what... how do I check... like, you're gonna check their references anyway, but it just gives you a little more confidence.

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Mai Pham: Um, in their abilities.

00:54:37.000 --> 00:54:39.000

Mai Pham: Does that make sense?

00:54:39.000 --> 00:54:44.000

Diane Frazier-Smith: So, so in other, so in other words, is, is, is, uh, like.

00:54:44.000 --> 00:54:50.000

Diane Frazier-Smith: With the self-direction, when you're going out there and you're finding.

00:54:50.000 --> 00:54:56.000

Diane Frazier-Smith: People to, uh... or, you know, according to your budget and whatever.

00:54:56.000 --> 00:54:59.000

Diane Frazier-Smith: You want these people to be...

00:54:59.000 --> 00:55:02.000

Diane Frazier-Smith: Professional, and majority of the time.

00:55:03.000 --> 00:55:05.000

Diane Frazier-Smith: They're not, because you're...

00:55:06.000 --> 00:55:09.000

Diane Frazier-Smith: Picking someone that may be...

00:55:09.000 --> 00:55:11.000

Diane Frazier-Smith: Um...

00:55:11.000 --> 00:55:14.000

Diane Frazier-Smith: Can help, you know, or...

00:55:15.000 --> 00:55:19.000

Diane Frazier-Smith: There's some kind of regulation that you have to have.

00:55:19.000 --> 00:55:24.000

Diane Frazier-Smith: When you're dealing with, uh, self-direction, and what you're implementing here.

00:55:25.000 --> 00:55:27.000

Mai Pham: Even without form...

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Diane Frazier-Smith: Does that make sense?

00:55:27.000 --> 00:55:35.000

Mai Pham: Yeah, even without formal recognition... sorry, regulation from the state, just being clear about what the training is.

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Mai Pham: And then, knowing that that person for sure knows about all these different sectors.

00:55:41.000 --> 00:55:47.000

Mai Pham: Because you can go out in self-direction and find someone who's really great with HCBS, but they don't know anything about healthcare.

00:55:47.000 --> 00:55:54.000

Diane Frazier-Smith: Right, right. That's... well, that's what I... that's what I'm saying. So, you're... you're implementing.

00:55:49.000 --> 00:55:51.000

Mai Pham: Right. And so that, that, it's...

00:55:51.000 --> 00:55:53.000

Mai Pham: Yeah.

00:55:54.000 --> 00:55:56.000

Diane Frazier-Smith: what action...

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Diane Frazier-Smith: Actually, what self-direction.

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Diane Frazier-Smith: Um, is not.

00:56:02.000 --> 00:56:04.000

Diane Frazier-Smith: Did I... am I...

00:56:04.000 --> 00:56:08.000

Diane Frazier-Smith: Saying that wrong, or is that a...

00:56:06.000 --> 00:56:15.000

Mai Pham: We're trying to make it holistic. Yeah, we're trying to make it holistic. I think self-direction varies from state to state, so I don't want to overgeneralize.

00:56:09.000 --> 00:56:11.000

Diane Frazier-Smith: You're making it holistic.

00:56:13.000 --> 00:56:16.000

Diane Frazier-Smith: Right, right, right.

00:56:15.000 --> 00:56:21.000

Mai Pham: But the idea is to have someone who's really confident in all those sectors.

00:56:21.000 --> 00:56:23.000

Diane Frazier-Smith: Okay, okay.

00:56:23.000 --> 00:56:25.000

Diane Frazier-Smith: Alright, thank you.

00:56:25.000 --> 00:56:31.000

Courtney Burke: Yeah, confident and competent, with a sort of credentialing that says, yes, you are...

00:56:25.000 --> 00:56:27.000

Mai Pham: Thanks.

00:56:31.000 --> 00:56:34.000

Courtney Burke: You have met this core competency.

00:56:34.000 --> 00:56:42.000

Diane Frazier-Smith: I mean, that, that, I mean, that makes sense, you know, um, because, uh, what you said before, uh, my...

00:56:34.000 --> 00:56:36.000

Courtney Burke: Okay.

00:56:42.000 --> 00:56:48.000

Diane Frazier-Smith: That a lot of people that are on self-direction, when they do choose these people.

00:56:48.000 --> 00:56:51.000

Diane Frazier-Smith: They, uh, might be in...

00:56:51.000 --> 00:56:53.000

Diane Frazier-Smith: uh...

00:56:53.000 --> 00:56:56.000

Diane Frazier-Smith: You know, professional in one area, but not.

00:56:57.000 --> 00:57:05.000

Diane Frazier-Smith: other areas, and stuff like that. You know, not in healthcare, you know, not in the educational piece, or, you know.

00:57:05.000 --> 00:57:09.000

Diane Frazier-Smith: And what the person actually needs.

00:57:09.000 --> 00:57:15.000

Diane Frazier-Smith: Because all of this involves the actual, uh, individual.

00:57:15.000 --> 00:57:19.000

Diane Frazier-Smith: And what their needs are, and how to critique.

00:57:19.000 --> 00:57:21.000

Diane Frazier-Smith: whatever they need.

00:57:22.000 --> 00:57:23.000

Courtney Burke: Exactly, yep.

00:57:23.000 --> 00:57:25.000

Diane Frazier-Smith: Okay, thank you.

00:57:24.000 --> 00:57:31.000

Courtney Burke: Thanks, thanks, Diane. We'll go to Danielle, and after Danielle, we'll go to Julie and Lucille. So, Danielle?

00:57:32.000 --> 00:57:38.000

Danielle Lanzetta: Hi, everybody. Hi, Courtney. Um, I kind of have the flip side to what...

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Danielle Lanzetta: she was talking about, for those on HHA and traditional home care.

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Danielle Lanzetta: How do we implement these rules and regulations while.

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Danielle Lanzetta: Trying to get...

00:57:51.000 --> 00:57:56.000

Danielle Lanzetta: So, like, if you want to take your HHA coordinator and have them work with you.

00:57:56.000 --> 00:58:09.000

Danielle Lanzetta: How do you get them to work with you the way you want, while not stepping on the toes of the traditional agency, and them saying, oh, so-and-so's not allowed to do this, so-and-so's not allowed to do that?

00:58:10.000 --> 00:58:13.000

Mai Pham: Well, there's... this model doesn't...

00:58:11.000 --> 00:58:13.000

Bj Stasio: You know, I take that one?

00:58:13.000 --> 00:58:15.000

Bj Stasio: Can I take that one, Mike?

00:58:14.000 --> 00:58:16.000

Mai Pham: Sure. Mm-hmm.

00:58:15.000 --> 00:58:17.000

Bj Stasio: Danielle...

00:58:18.000 --> 00:58:21.000

Bj Stasio: You know I'm gonna be real with you for a second.

00:58:20.000 --> 00:58:24.000

Danielle Lanzetta: And I know where you're going, but think about it from the way I'm saying it.

00:58:24.000 --> 00:58:36.000

Bj Stasio: I get it, I get it, but that's where... that's where the... that's where the rough advocacy comes in, that we always talk about together. You have... you have to not...

00:58:36.000 --> 00:58:42.000

Bj Stasio: Rely on the agency so much, and just be authentically you.

00:58:42.000 --> 00:58:44.000

Bj Stasio: Because there's so...

00:58:43.000 --> 00:58:52.000

Danielle Lanzetta: I know that, but when you're dealing with rules and regulations, that if you are in traditional care versus self-direction.

00:58:52.000 --> 00:58:56.000

Danielle Lanzetta: How do you balance the two without...

00:58:56.000 --> 00:59:02.000

Danielle Lanzetta: Pardon my French, pissing off the coordinators and while still staying on the good side while getting what you need.

00:58:59.000 --> 00:59:18.000

Bj Stasio: You don't... you don't have to worry about balance, you have to think about what is right for you, because then it will be right for somebody else if you build that bridge to make that change. It's all about building a bridge to make a change, and sometimes you have to flip the boat over.

00:59:18.000 --> 00:59:34.000

Bj Stasio: to create the change. Instead of trying to rock the boat, you might have to flip it over, and that's where... that's where I'm at the point in my life. I'm just ready to flip the boat over and see what the new boat looks like after they rebuild it, after I.

00:59:34.000 --> 00:59:41.000

Bj Stasio: flip it over, I'm... I... because I've been in the system long enough as you have, and I'm tired of, like, you know.

00:59:41.000 --> 00:59:53.000

Bj Stasio: worrying about pissing people off. Mai knows this, and I've said this to Mai when we've sat together. I look to piss people off every chance I get, because they're more likely to listen.

00:59:53.000 --> 00:59:55.000

Bj Stasio: When I piss him off.

00:59:53.000 --> 00:59:57.000

Mai Pham: So, Danielle, I want to clarify that.

00:59:57.000 --> 01:00:03.000

Mai Pham: Um, you know, we're not presenting this model as somehow pushing aside every other model.

01:00:03.000 --> 01:00:07.000

Mai Pham: This is really about giving the person another option.

01:00:08.000 --> 01:00:15.000

Mai Pham: Um, and I don't know the rules, uh, around self-direction versus not in New York well enough.

01:00:15.000 --> 01:00:18.000

Mai Pham: To, like, really answer your question in depth.

01:00:18.000 --> 01:00:22.000

Mai Pham: But I would say, like, you can imagine, you know, using your current.

01:00:22.000 --> 01:00:27.000

Mai Pham: Coordinator for some things, and then using this other person for other things.

01:00:27.000 --> 01:00:31.000

Mai Pham: That cross more into those other sectors, as one example.

01:00:30.000 --> 01:00:42.000

Danielle Lanzetta: Because basically, what happens is, with HHA, is they... you have a set of... you have a set number of hours, and the coordinators have a list of do's and don'ts, and then how do you.

01:00:42.000 --> 01:00:45.000

Danielle Lanzetta: My question is, how do you bridge the two?

01:00:46.000 --> 01:00:48.000

Danielle Lanzetta: Successfully, without...

01:00:50.000 --> 01:00:53.000

Danielle Lanzetta: Without getting on...

01:00:50.000 --> 01:00:53.000

Mai Pham: Yeah, so if you...

01:00:53.000 --> 01:00:55.000

Danielle Lanzetta: Either bad...

01:00:53.000 --> 01:01:01.000

Mai Pham: This person, if you had this other person, that other person could take that job off of your shoulders.

01:01:01.000 --> 01:01:04.000

Mai Pham: They would work with your HHA coordinator.

01:01:05.000 --> 01:01:07.000

Mai Pham: Does that make sense?

01:01:06.000 --> 01:01:08.000

Danielle Lanzetta: Yeah.

01:01:07.000 --> 01:01:09.000

Mai Pham: Yeah.

01:01:08.000 --> 01:01:12.000

Courtney Burke: Great, great. All right, we're gonna do two more questions, and then, um...

01:01:13.000 --> 01:01:17.000

Courtney Burke: We'll do a closing and let you know about the upcoming webinars, so...

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Courtney Burke: Uh, truly.

01:01:18.000 --> 01:01:26.000

Julie Owen (she/her): Yeah, hi, thanks everyone. Julie Owen with Heritage Christian Services, and I kind of had a two-parter. One.

01:01:26.000 --> 01:01:31.000

Julie Owen (she/her): Um, I'd like to hear more, um, of your perspective on what role.

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Julie Owen (she/her): technology plays, so for somebody to be interfacing with multiple networks navigating some complex systems, I'm wondering if your pilot takes into account, uh, technology that would support those efforts?

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Julie Owen (she/her): And then a follow-up question, um...

01:01:48.000 --> 01:01:56.000

Julie Owen (she/her): maybe slightly unrelated. Um, can you tell me more about your thoughts about this? This one person becomes...

01:01:56.000 --> 01:02:03.000

Julie Owen (she/her): Um, exceptionally important. The one person you're relying on to help navigate multiple systems.

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Julie Owen (she/her): And as Courtney shared in the introduction, we're all navigating a system where there are significant workforce.

01:02:12.000 --> 01:02:23.000

Julie Owen (she/her): challenges. Um, and so I'm wondering how the pilot takes into account when there is, um, you know, somebody who may leave, whether voluntarily or not.

01:02:23.000 --> 01:02:34.000

Julie Owen (she/her): Um, if they are the holder of all, and the navigator of all of these different complex systems, how do you envision continuity, um, given those challenges?

01:02:34.000 --> 01:02:38.000

Mai Pham: Yeah. So, on your first question.

01:02:38.000 --> 01:02:42.000

Mai Pham: I don't think our ambition is for this humble model to.

01:02:42.000 --> 01:02:47.000

Mai Pham: Fix the inadequate data systems in the world.

01:02:48.000 --> 01:02:53.000

Mai Pham: Um, so I don't... I don't think that any single individual professional can do that.

01:02:53.000 --> 01:02:56.000

Mai Pham: We're really talking about someone who is.

01:02:56.000 --> 01:03:00.000

Mai Pham: Competent enough to deal with the imperfect world as it is.

01:03:00.000 --> 01:03:06.000

Mai Pham: That said, I will say that, um, last year I learned of a tech-enabled startup.

01:03:06.000 --> 01:03:10.000

Mai Pham: in California that offers a flavor of this.

01:03:10.000 --> 01:03:14.000

Mai Pham: Already, where, um, they hire...

01:03:14.000 --> 01:03:18.000

Mai Pham: parents. It's mostly a pediatric model. They hire parents.

01:03:18.000 --> 01:03:22.000

Mai Pham: Um, to serve as the interface with clients.

01:03:22.000 --> 01:03:27.000

Mai Pham: But then, they have a database of all the relevant services, mostly.

01:03:28.000 --> 01:03:33.000

Mai Pham: educational and HCBS services available in this pocket of California.

01:03:33.000 --> 01:03:43.000

Mai Pham: Um, and behind the parents, behind the scenes, are social workers and nurses who provide the, you know, the technical expertise.

01:03:43.000 --> 01:03:53.000

Mai Pham: Um, so, in that sense, you can imagine, you know, entrepreneurs getting really creative about tools that these navigation support people might need.

01:03:53.000 --> 01:03:56.000

Mai Pham: And might want to purchase. On your second question.

01:03:57.000 --> 01:04:00.000

Mai Pham: it's, um... I smiled a little bit because.

01:04:00.000 --> 01:04:04.000

Mai Pham: It's the same issue that I have with my therapist.

01:04:05.000 --> 01:04:07.000

Mai Pham: Right? Whom I've been with for 15 years.

01:04:08.000 --> 01:04:23.000

Mai Pham: Uh, what am I gonna do when he retires? He's a few... just a few years older than me, but, you know, he's making noises, like he really wants to set up his music studio, and that just makes me super anxious. Well, when... when a dentist retires, when a therapist retires, if they are.

01:04:23.000 --> 01:04:25.000

Mai Pham: Worth their salt.

01:04:25.000 --> 01:04:29.000

Mai Pham: They help you find... like, they help with the warm handoff.

01:04:29.000 --> 01:04:39.000

Mai Pham: They give you recommendations on whom else to, um, to look at as their successor, and they do that warm handoff so that there isn't a gap, there isn't a void.

01:04:40.000 --> 01:04:53.000

Mai Pham: Can't speak to what happens if someone is, God forbid, hit by a bus, right? But I think that it's not a different problem than we have in... with any other professional with whom, you know, you form a close bond.

01:04:57.000 --> 01:05:09.000

Courtney Burke: Great answer, thank you. Thanks for the question as well. And we'll wrap up with, uh, Lucille. I did see the comment in the chat about the fiscal viability, so if we have time just to address that at the end, we will. But Lucille?

01:05:09.000 --> 01:05:11.000

Lucille Rossi: Yeah, thank you. Um, my question is.

01:05:12.000 --> 01:05:28.000

Lucille Rossi: I'm a parent, my daughter's 25, and I'm navigating, you know, the system. We use self-direction successfully. And, you know, I... my daughter's 25, and I often say it's taken me 25 years to figure out how most of the systems work today. And, you know, I...

01:05:29.000 --> 01:05:31.000

Lucille Rossi: I don't delude myself, I know more...

01:05:32.000 --> 01:05:41.000

Lucille Rossi: details on how things work than my care manager, but my... or my daughter's care manager, but, you know, the bar is quite low. It's, you know, I just...

01:05:41.000 --> 01:05:55.000

Lucille Rossi: make sure that he can do the paperwork correctly and on time, right? So, but I'm navigating all those other things. So your system sounds great in terms of what, um, you know, what you guys could, you know, what the system could offer, but the biggest problem.

01:05:55.000 --> 01:05:59.000

Lucille Rossi: Is that there's no thing that.

01:05:59.000 --> 01:06:01.000

Lucille Rossi: There's no there.

01:06:01.000 --> 01:06:04.000

Lucille Rossi: There's no... nothing that they can do to...

01:06:04.000 --> 01:06:09.000

Lucille Rossi: that solves the question that your person needs to do. So, for example.

01:06:09.000 --> 01:06:13.000

Lucille Rossi: You know, two of the biggest categories are housing and employment.

01:06:14.000 --> 01:06:19.000

Lucille Rossi: Right? So, regardless of you having, like, a great navigator helping somebody.

01:06:20.000 --> 01:06:24.000

Lucille Rossi: There's no system in place for someone to get employment.

01:06:24.000 --> 01:06:29.000

Lucille Rossi: And there's, like, I don't know, a suboptimal system in place for people to get housing.

01:06:30.000 --> 01:06:34.000

Lucille Rossi: So, regardless of who is navigating.

01:06:34.000 --> 01:06:36.000

Lucille Rossi: The system isn't working right.

01:06:37.000 --> 01:06:40.000

Lucille Rossi: So, there needs to be an overlying...

01:06:40.000 --> 01:06:43.000

Lucille Rossi: Infrastructure Architecture.

01:06:43.000 --> 01:06:45.000

Lucille Rossi: That fixes that stuff.

01:06:46.000 --> 01:06:49.000

Lucille Rossi: In parallel, or before?

01:06:49.000 --> 01:06:53.000

Lucille Rossi: Because you can't get any of these things done.

01:06:54.000 --> 01:06:56.000

Lucille Rossi: otherwise.

01:06:56.000 --> 01:06:58.000

Mai Pham: So... yeah.

01:06:56.000 --> 01:06:59.000

Lucille Rossi: So, good luck, you know.

01:07:00.000 --> 01:07:01.000

Mai Pham: Sorry, I didn't mean to interrupt.

01:07:01.000 --> 01:07:03.000

Lucille Rossi: Yeah, no, I was just gonna say, you know.

01:07:02.000 --> 01:07:04.000

Mai Pham: Yeah.

01:07:03.000 --> 01:07:08.000

Lucille Rossi: You could have the best people involved, you just can't get employment. Our systems don't support it.

01:07:09.000 --> 01:07:13.000

Mai Pham: Don't hold me to this, because I have middle-aged memory now, but.

01:07:13.000 --> 01:07:19.000

Mai Pham: I have a vague memory that Karen Davis and other economists at Hopkins once estimated.

01:07:19.000 --> 01:07:27.000

Mai Pham: That to meet all unmet need, and this was a decade ago, which means the number is even larger today, we'd need to be prepared to spend \$10 trillion.

01:07:27.000 --> 01:07:37.000

Mai Pham: over 10 years. Um, which we're clearly not going to do nationally. So I agree with you, Lucille, there's a lot that this prob- this model will not solve.

01:07:37.000 --> 01:07:44.000

Mai Pham: And we don't pretend that it will. But as it is, even with the services that are out there.

01:07:44.000 --> 01:07:46.000

Mai Pham: a lot of people can't get to them. Like.

01:07:47.000 --> 01:07:50.000

Mai Pham: My child, Alex, who's next door, um.

01:07:51.000 --> 01:07:53.000

Mai Pham: uh...

01:07:53.000 --> 01:07:57.000

Mai Pham: is not in OPWDD and DC.

01:07:57.000 --> 01:08:01.000

Mai Pham: Um, we feel kind of guilty doing that, because we've got resources.

01:08:01.000 --> 01:08:05.000

Mai Pham: And when we were... when he was getting RSA services.

01:08:05.000 --> 01:08:10.000

Mai Pham: Um, I didn't think they were particularly high value, so we're making it up.

01:08:10.000 --> 01:08:12.000

Mai Pham: We're completely making it up.

01:08:10.000 --> 01:08:12.000

Lucille Rossi: Mhm.

01:08:12.000 --> 01:08:17.000

Mai Pham: Right? So there are people like us, there are people who don't have...

01:08:18.000 --> 01:08:24.000

Mai Pham: the capacity to even get... even if they qualify, they don't have the capacity to get into the OPWDD system.

01:08:23.000 --> 01:08:25.000

Lucille Rossi: Mhm. Mm-hmm.

01:08:24.000 --> 01:08:32.000

Mai Pham: Right? And so there are just lots of ways that you can fall through the gaps. That's even before you get to solving the big.

01:08:30.000 --> 01:08:32.000

Lucille Rossi: Yeah.

01:08:32.000 --> 01:08:34.000

Mai Pham: You know, access, like.

01:08:33.000 --> 01:08:38.000

Lucille Rossi: But we have all these systems in place, like, we've got.

01:08:34.000 --> 01:08:36.000

Mai Pham: financing issues.

01:08:38.000 --> 01:08:40.000

Lucille Rossi: so many...

01:08:40.000 --> 01:08:47.000

Lucille Rossi: groups. We've got the GDAC, and the CDD, and the family stakeholders, and we're...

01:08:47.000 --> 01:08:51.000

Lucille Rossi: We just spent tons of money, and we have an 800-page.

01:08:51.000 --> 01:08:58.000

Lucille Rossi: Um, a report from... about self-direction, another 800 report about care management, and...

01:08:58.000 --> 01:09:02.000

Lucille Rossi: There's no... you can... you... there's no...

01:09:03.000 --> 01:09:05.000

Lucille Rossi: Shortage of recommendations.

01:09:06.000 --> 01:09:08.000

Lucille Rossi: There's so many recommendations.

01:09:08.000 --> 01:09:12.000

Lucille Rossi: And you've got... some of the people on this call here are experts.

01:09:12.000 --> 01:09:14.000

Lucille Rossi: in the state.

01:09:15.000 --> 01:09:20.000

Lucille Rossi: Totally knowledgeable experts, and probably could fix most of the problems.

01:09:20.000 --> 01:09:22.000

Lucille Rossi: by next Thursday, you know?

01:09:22.000 --> 01:09:24.000

Lucille Rossi: It's just, we never get them done.

01:09:25.000 --> 01:09:27.000

Lucille Rossi: And there's tons of low-hanging fruit.

01:09:27.000 --> 01:09:29.000

Lucille Rossi: That we could fix in a minute.

01:09:29.000 --> 01:09:33.000

Lucille Rossi: Like, you know, I... not a day goes by.

01:09:32.000 --> 01:09:38.000

Mai Pham: Yeah, I, I defer... yeah, I defer to the New York experts on all of that. This is...

01:09:36.000 --> 01:09:40.000

Lucille Rossi: Yeah. He just can't get anything fixed.

01:09:39.000 --> 01:09:41.000

Mai Pham: Yeah.

01:09:41.000 --> 01:09:46.000

Lucille Rossi: We can't even find out... I can't even tell you, in my county, how many.

01:09:41.000 --> 01:09:43.000

Courtney Burke: Yeah, and I'll jump.

01:09:46.000 --> 01:09:50.000

Lucille Rossi: Agencies have openings for an employment service.

01:09:50.000 --> 01:09:54.000

Lucille Rossi: I can't tell you that. There's nobody in New York... there's nobody in...

01:09:55.000 --> 01:09:56.000

Lucille Rossi: There's nobody in New York who can tell me.

01:09:57.000 --> 01:10:01.000

Lucille Rossi: How many agencies have an opening in an employment service?

01:10:02.000 --> 01:10:06.000

Courtney Burke: Yeah, and I... I don't mean... I don't mean to interrupt Lucille. No, I pop...

01:10:02.000 --> 01:10:04.000

Lucille Rossi: So we can't follow...

01:10:04.000 --> 01:10:06.000

Lucille Rossi: I don't... I'm just giving you an example.

01:10:06.000 --> 01:10:10.000

Lucille Rossi: We have lots of low-hanging fruit, and we can fix those things.

01:10:07.000 --> 01:10:09.000

Courtney Burke: I apologize.

01:10:10.000 --> 01:10:12.000

Lucille Rossi: And it would serve everyone.

01:10:12.000 --> 01:10:16.000

Courtney Burke: Yeah, I agree, but I know we have to wrap up, because it is...

01:10:14.000 --> 01:10:16.000

Lucille Rossi: Thank you.

01:10:16.000 --> 01:10:23.000

Courtney Burke: 5 o'clock, and there... I think you are very transparent, my Pham, that this is not solving all problems.

01:10:23.000 --> 01:10:32.000

Courtney Burke: But I thought that there were a lot of really, really great features of this model. I would love for you to have your wish come true to be queen of the world for a day and get...

01:10:32.000 --> 01:10:36.000

Courtney Burke: The services and supports that you need to try it out.

01:10:36.000 --> 01:10:42.000

Courtney Burke: Because I really like the components of it, what it does to empower people, what it does to empower DSPs.

01:10:43.000 --> 01:10:54.000

Courtney Burke: So, thank you, and Danielle, I'm sorry that we didn't get back to you. Um, we do have to wrap up, and I wanted to just make sure that Ryan could tell us about the two upcoming webinars that we have planned.

01:10:54.000 --> 01:10:56.000

Ryan Cox: Yep, and I'll be brief, I know that we're kind of...

01:10:54.000 --> 01:10:58.000

Mai Pham: And I apologize, I have a call I have to drop off for, but.

01:10:57.000 --> 01:11:00.000

Courtney Burke: Thank you again, my fam, this was awesome.

01:10:57.000 --> 01:10:59.000

Ryan Cox: Bye.

01:10:58.000 --> 01:11:03.000

Mai Pham: Danielle, if you... if you collect other questions, I'm happy to answer them offline.

01:11:00.000 --> 01:11:02.000

Courtney Burke: This was awesome.

01:11:02.000 --> 01:11:04.000

Courtney Burke: Okay, yep.

01:11:03.000 --> 01:11:05.000

Diane Frazier-Smith: Thank you, Maya. Thank you.

01:11:04.000 --> 01:11:06.000

Mai Pham: Thank you, everyone.

01:11:04.000 --> 01:11:07.000

Ryan Cox: Thanks so much, Mai. Thank you so much.

01:11:05.000 --> 01:11:07.000

Courtney Burke: Yep.

01:11:05.000 --> 01:11:07.000

Diane Frazier-Smith: Thank you.

01:11:07.000 --> 01:11:23.000

Ryan Cox: So just real quick, before everybody jumps off, I just wanted to let you know that we are scheduling a webinar in December. We're gonna have Joe McBeth and Dan Hermrich from the National Alliance for Direct Support Professionals, and we're gonna pivot a little bit and talk about our third theme, which is strengthening the frontline workforce.

01:11:23.000 --> 01:11:39.000

Ryan Cox: So, they're gonna come in and talk about some of the work that they've done in New York, but also work that they've done in other states. Pennsylvania has a very interesting model that NADSP has been working with, um, that reimburses providers directly for the number of certified individuals that they have within their workforce, so very interesting.

01:11:39.000 --> 01:11:46.000

Ryan Cox: kind of different model from Pennsylvania. And then in January, we're gonna have Amy Hewitt from the University of Minnesota.

01:11:46.000 --> 01:12:00.000

Ryan Cox: Institute on Community Inclusion, and, um, she's going to talk about a lot of the different innovative things that they've been doing in the workforce space across many different states. So, Joe, um, and his team from NADSP in December, and Amy.

01:12:01.000 --> 01:12:03.000

Ryan Cox: Um, in January, and we're gonna send...

01:12:01.000 --> 01:12:03.000

Diane Frazier-Smith: What's the date?

01:12:03.000 --> 01:12:05.000

Ryan Cox: the...

01:12:03.000 --> 01:12:05.000

Diane Frazier-Smith: Do you have the dates, Ryan?

01:12:05.000 --> 01:12:15.000

Ryan Cox: We're gonna be sending these out, Diane, as part of a larger communication from this listserv, but it's December 10th and then January 13th, but you'll get an email.

01:12:09.000 --> 01:12:11.000

Diane Frazier-Smith: Okay, alright.

01:12:12.000 --> 01:12:13.000

Diane Frazier-Smith: Okay.

01:12:14.000 --> 01:12:16.000

Diane Frazier-Smith: Okay. Okay.

01:12:15.000 --> 01:12:18.000

Ryan Cox: Well, you'll get an email to Obuster with all the involvedness.

01:12:17.000 --> 01:12:20.000

Diane Frazier-Smith: This way, I can block it, I can block that day.

01:12:20.000 --> 01:12:22.000

Ryan Cox: You got it.

01:12:20.000 --> 01:12:22.000

Diane Frazier-Smith: Okay? Alright.

01:12:21.000 --> 01:12:26.000

Courtney Burke: Yeah, December 10th at 3pm and January 13th at 1pm right now is what we have held.

01:12:27.000 --> 01:12:29.000

Diane Frazier-Smith: Okay. Um...

01:12:27.000 --> 01:12:30.000

Ryan Cox: Tentatively, so... but we'll let you know when it's final.

01:12:28.000 --> 01:12:35.000

Courtney Burke: Tentatively, yeah, tentatively. So we'll send that, send out a communication. So thank you. Thanks, everybody. Thanks, Ryan.

01:12:29.000 --> 01:12:31.000

Diane Frazier-Smith: Okay, no problem.

01:12:34.000 --> 01:12:36.000

Ryan Cox: Thanks, everybody. Bye-bye.