BRUCE DARLING: All right everyone.

The quick break is over.

We'll get the real break in, I don't know, 40 minutes.

Well, 35, whatever it turns out to be.

10:15, wait what time is the break Tim?

This is why 10, okay.

Thank you so much.

How are you all doing this morning?

All right, we could be a little more excited than that.

How are you all doing this morning?

All right.

Well, actually, that's a great lead in to the next slide.

It says as a result of this learning and sharing experience it is hoped that you'll be able to, and I will go through the rest of the slide.

But the important thing is this is a learning and sharing experience, it's not a usual training.

So when you're coming into this thinking, like, we're going to tell you everything and we are the people who are the know it alls who are going to guide you through this process.

OK, spoiler alert, that ain't going to happen.

And actually, to be perfectly honest, that was some of my reluctance about this training is because, it is very open, there's a lot of interpretation.

We have to actually figure a way forward for the collective of independent living for the entire community.

Some of what we're trying to do is noodle through some of these issues.

So it is not the standard training.

We're really expecting you to participate in this and help us through the thinking process cause there are a lot of angles on this.

So of the learning objectives we're going to describe the necessary elements of independent living services that implement the new core service requirements for institutional transition and diversion.

So that is getting people out of institutions and preventing them from going in.

Describe the interconnected needs of individuals with significant disabilities.

Describing how the interconnected needs of individuals with significant disabilities guide both transition and diversion from institutions.

While we're talking about interconnected needs, some people were talking about the funding for the services, other people were talking about the housing.

All of these pieces have to fit together in just the right way in order for folks to transition into the community and stay in the community.

So that is really going to, they are all very much interconnected and it's important that we understand all of them.

We're going to describe approaches for identifying and assisting at risk individuals to avoid placement in institutions.

You'll get some best practices on that.

We'll describe successful implementation strategies for diversion and transition that include funding, relationships, referrals, and leveraging the other core CIL services.

I heard funding come up a lot, also heard a lot of folks from California, when we were going through the tables, it just struck me a lot of folks from California here, so that's exciting.

But we're going to talk specifically, I will actually end later on in this presentation, day 3, talking about the funding piece of this.

All right.

So over the next two and a half days, we will share our experiences, okay.

Again, underscore that.

We'll be looking to you to share what you're doing and what your thoughts are on this.

We'll provide some information on effectively assisting institutional transition and diversion.

So what is it that is, so a lot of us, I think, when we've done this training from the other side, so I have done actually a lot of training on nursing facility transition.

I was looking and I think it's been, Tim can correct me if I am wrong, been like 14 years of this so actually, I think Wendy pointed out, Bruce, your hair has gotten very gray.

We are much more gray than we were.

Having done this, one of the things we talked about when we were doing, talking about transition, was we were already preventing people from going in, we just needed to use those same skills.

Now I feel after 14 years, we're circling back around and trying to wrap our head around how do we keep people out and what does that actually look like.

Answer questions on the transition and diversion process, I think that's in part why Darrel Jones asked me to be on this.

I have had a lot of experience in transition and can answer a lot of questions on that, as well as the other presenters.

They have a lot of experience dealing with this.

We're bringing that expertise, but looking around the room, I see a lot of people who have either been to prior trainings or doing the work or have presented at other trainings on this.

So there's a lot of collective expertise in the room that we are going to draw on as well.

And then facilitate peer sharing of ideas and experiences.

Okay, so again, you're hearing this a half a dozen times in the first five minutes.

We are really wanting to lay the groundwork that this is really a collaborative process that we're going to be working through.

Okay.

So the overarching principles.

Assisting someone in reclaiming their, in reclaiming and maintaining their life and moving into and staying in the community are fundamental to independent living.

These two overarching principles, you wouldn't think like there's going to be a lot of disagreement or conversation around them.

I would be, you might be surprised.

Over 14 years the experience I've had when we talk about these two principles, the second one being the independent living philosophy answers many of your questions and guides you through the process.

I have actually seen people have walked out of trainings, people have gotten into arguments in trainings, people have called each other out saying, that's not independent living.

So I would like to reinforce, these are the overarching principles, but there is a lot of interpretation.

I want to start out where I'm at so you have a sense of what my background and what my thoughts are on this.

I'm open to being told, Bruce, that's absolutely wrong, but I think at the end you'll say he's sort of in the middle ground on this.

So we're assisting someone, I think the first point, we're assisting someone in the process.

So one of the things that's important in independent living, and I was describing this to my staff, they said, what is, how did independent living come about?

I said basically we started to do these core services, because no one else was doing them, and they were things that people with disabilities needed.

What's been interesting across the last couple of decades, is as nursing facility transition and these things have been more formalized and more funding streams have been available, a lot of traditional providers have come into the mix, and sometimes transition is actually something that people do TO an individual with a disability or FOR an individual with a disability.

And ultimately, that can really undercut what you're trying to accomplish.

Because, think about it.

You're in a setting where every last decision is made for you.

You don't really get to choose much of anything in your life.

Your schedule is fixed.

You want to help support someone move into a place where they're actually making their own decisions and taking control of their life.

If you do that by taking over the process for the person and doing it to them or for them, okay, on the other side, they're not going to be prepared for what they need to do.

They won't have the skills if you're doing it that way.

So it's really important, from my perspective, in terms of independent living but also in terms of the desired outcome that we're supporting the individual through the process.

Now, on the other end of the spectrum, I have also seen centers say things like: I get a call, can you come down to, can you drive three hours to help this, help me get out of a nursing facility?

I'm thinking there's center right in that area, I'm just going to take, rather than me go three hours, I will just call the local center.

Response I got was, that is our founding board president, he's in a nursing facility right next door.

If he wants to get out, he should just get out of that damn bed, come over in the front door, do an intake and we'll help him get out.

But we're not going to go over there and help him until he does all the things he needs to do to come in the door and get this done.

All right.

Woah, I did not expect that conversation at all.

I was sort of stuck on founding board president.

So in my mind, I'm thinking, you know what?

If you were the founding board president of a center, you kind of get points for that, and I will go out of my way to do whatever needs to be done to help you.

But even if you were not the founding board president of a CIL, we have to recognize that sometimes people need, there are barriers to accessing services, and we should not be using the independent living philosophy as a barrier to getting services and supports.

So, I also saw it in another way.

So a local developmental disability agency had worked with a woman get out of an institution, out of an ICF, actually.

They moved her, actually.

They moved her into a house in the suburbs of Rochester.

It's cold, for folks in California, the south, it's cold in Rochester in the winter.

Some places are much colder.

This was a suburb, there wasn't a lot of wind protection, she had electric heat in the house.

Okay, this was not a sustainable situation.

She had several roommates.

As it turns out, first roommate finds a man and moves off with him.

Second roommate has some other issues, she moves out.

So here is this woman.

She has SSI, an 800-dollar a month rent on this house, and an electric heat bill that's just completely off the charts.

In the middle of winter.

The agency says to me, well, she knew what she was getting into.

This is independent living.

She's responsible for figuring it out.

Okay.

No.

Now we're using independent living as a weapon.

You made a decision as an agency, you set this situation up, and this poor woman, she came to us, she's like crying, I can't figure out how to pay the bill.

I looked, I said, honey, you can't pay the bill.

I mean, there's not enough money in the budget to even pay either the rent or the electric.

Much less eat and get your other needs met.

For me, I'm in the middle ground here.

So independent living isn't all you're completely on your own.

Maybe we'll give you some information.

Probably worked back in the days of Ed Roberts, when folks had the, that may have been good, but today not so much.

And doing for and taking control totally, I'm right in the middle of all of this.

The person is in charge, we want to support people through the process, but we also want to make sure that we're not putting up barriers to their moving forward.

So you can see how some of these issues could, we're naturally, okay.

So service delivery.

How many folks do this really like helping people do this?

Okay.

So initially not a lot of hands went up, which made me very nervous.

At least half of the folks.

And that's 15 minutes to the 10:00 o'clock time?

I wrote all my times on here.

This is useless now.

All right, so where was I?

We want to help people.

We are naturally inclined to help people and jump in.

Okay, so sometimes for us, it can be painful to like have a person, I don't know, even the truest in independent living, if you care about people, sometimes it's really hard to watch something implode.

So we have to really sort of pay attention to: are we supporting the person through the process?

Are we stepping in and putting our own values on top of things?

So it really is important that we watch those and pay attention.

Any thoughts or feedback on this?

Anyone disagree?

Wendy, let's get the microphone.

I'm sorry.

I didn't warn the mic running people.

AUDIENCE MEMBER: This is Wendy.

I'm just so glad to hear you say that Bruce, because I have been right in the middle with you for the last two years, and I'm just completely puzzled how to best work with the other agencies that have come in, because they either want total control or they extremely risk a person, they keep telling people I have been working with for years that they can't move unless they have somebody living with them.

Once they say that, they call it a safe and healthy transition and they kick that person to the curb and they put my name on a piece of paper and say, call Wendy, because she can do it anyway.

But they have all the money.

BRUCE DARLING: Right, well and I think, we'll talk a little bit about that, but Wendy thank you for bringing up the point.

Because for a lot of these traditional provider folks, risk is a big issue for them, and they will look at a situation and they'll say, you know, that's not safe.

And the threshold for safety can be very, very high for folks.

So this applies both in transition and diversion.

So in transition, you know, they'll say, we're not letting this person move out, which eventually they do, but we're not letting them move out, we're not sanctioning this transition unless this is perfectly safe, which is a threshold that even my life does not hit.

If we're going to talk, we're going to need the microphone.

Sorry.

AUDIENCE MEMBER: So I just, one of the things that's happened is that I had a person years ago who refused to participate in the program because their paperwork says that if they decide that you have to go back in, then they decide that you have to go back in.

And if you sign that paperwork, you're stuck, have you no say in the matter whatsoever.

BRUCE DARLING: I think that's where, I've seen that in traditional providers and sometimes the providers and the funding, the kind of control that the state puts over some of these funding streams actually begins to bleed down into our systems, and I've watched centers struggle with some of these issues in terms of where the state was saying, we need to hit this bar, and it wasn't actually, it under cut the choices of the individual.

But how you navigate through that.

Tim?

AUDIENCE MEMBER: I'm sorry.

When you say "they" who are you referring to?

BRUCE DARLING: Okay, it could be, so they is the others.

So I am thinking basically, when we're dealing with this, we're talking about the institutional bias, it ultimately becomes almost everyone but us sometimes.

So sometimes it's the state, its your funding stream, so they will put into your contract requirements.

Sometimes it's the nursing facility who wants to keep people there or keep their beds filled.

It may be the home care providers.

So I'm going to talk about this a little bit more later, but the home care providers may look at someone and say, oh, God, you're really disabled, and we're going to stop providing your assistance if an aid doesn't come to your house.

I don't want to deal with you.

We have this quote requirement in New York where you have, like home care agencies will say, you must live with someone to have that informal backup, because they tend not to cover the cases.

We actually had a report, it's older now, but 30 to 40% of the time home care wasn't actually covering the hours.

So think about that in your life, 30 to 40% of the time, you can't get out of bed or eat or go to the bathroom.

Maybe 30 to 40% doesn't seem like a lot to you, but it seems like a lot to me.

But I'm diabetic, I like to use the rest room.

So it's kind of a thing.

You may get push back from a lot of different places.

And you're from where?

Michigan, okay.

So you've had a lot of transition work, you have a pretty robust waiver system there.

AUDIENCE MEMBER: Yes, and the one thing that I did learn from the conference is the difference in all of the states, because we, like you just mentioned about the home health care agency not servicing someone because they didn't have, because they didn't live with someone.

That doesn't happen with us in Michigan.

BRUCE DARLING: What you're going to find is the saying is if you've seen one Medicaid program, you've seen one Medicaid program.

And across the country, there's going to be a lot of variation in this, and I would be thrilled, like if that were the case in New York, I would be thrilled.

But I also know that there's other gaps and problems in various states.

So the thing is, not one state has everything lined up the way it should be.

We're all facing various kinds of barriers.

I appreciate you asking.

For me, it was infuriating in New York.

I couldn't understand.

I would say, this is America.

If you make widgets, you make money.

I would think intuitively, if you make more widgets, you make more money.

But actually New York did some really perverse things in its Medicaid rate system.

They actually disincentivized providing lots of hours of service.

So it ended up that home care agencies would actually lose money when they took on cases like this.

And then the liability was significant as well.

So it's important to know that these are the guiding principles that they are things that we are going to follow, but not necessarily everyone else is going to abide by or agree with.

All right.

Tim, I'm watching.

I think I have five minutes.

All right.

Institutional transition diversion work are based on the Americans with Disabilities Act.

And I will probably end up breaking this in the middle.

So folks who have been through these trainings a bazillion times across all of 14 years, you probably all can do this, but Title II of the ADA, state and local governments, basically it says services must be provided in the most integrated setting, a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.

So I talked about it like this.

Sort of the dirty little secret.

Yes, Congress was talking about institutionalization, but when we were writing Title II, not me personally, but when these regs in Title II were being written, were people actively thinking about community integration out of institutional settings?

No.

Absolutely not.

If you go back in the literature, you can see there was actually some vigorous upset by folks saying the issue that was not addressed was the institutionalization of people with disabilities.

Applying the ADA in this work is the brain child of Steve Gold.

I want to give him credit for this.

He's the one who came up with the idea that who pays for institutional placement generally?

States.

So therefore, who pays for community based services?

States.

Medicaid.

Medicaid for better or for worse is a state program.

So there's federal participation, but it's run jointly by the state and federal government.

So Title II applies.

With that what we will do, I think I'm at 10, so we'll do a 15 minute break?

TIM FUCHS: Let's take a 15 minute break and we'll pick up right where you left off.

BRUCE DARLING: Okay.

Cool.

Thanks.

(break) BRUCE DARLING: All right.

Let's come back.

All right.

So when we broke, rather abruptly, because I was trying to watch the time, we were talking about the Americans with Disabilities Act, Title II, how long term services and supports are basically a state service, and Steve Gold came up with this concept that those services needed to be provided consistent with the rules of Title II, in the most integrated setting.

I will just highlight.

It is the most integrated setting, sometimes we'll slide back into language about the least restrictive environment.

ADA was actually more positive.

And its language we actually leverage in terms of people being in the most integrated setting.

So the Supreme Court case, which a lot of folks have heard about, was Lois Curtis and Elaine Wilson, they sued the state of Georgia.

It's kind of cool to be here in Georgia doing this training.

But the original case actually was out of Pennsylvania and the people in that case generally are not acknowledged, because it was settled in the Pennsylvania courts.

It basically, so I just want to give Helen L, Beverly D, Ilene F, Florence H and Idelle S.

Those are the women in Pennsylvania who were fighting to get services and supports in the community.

What's interesting with Olmstead is because Lois Curtis and Elaine Wilson had mental disabilities, people tend think of it, and because of the bias of the P and A system primarily, people think of Olmstead as being something for people with mental health or developmental disabilities because that's what the preponderance of cases were.

The original cases weren't actually about people with mental health or developmental disabilities, it was about physical disabilities and getting those services and supports in the community.

So it's important to realize this is cross disability.

So there is no diagnosis in Title II.

It's not a program bill.

It's a civil rights bill.

So it applies to people with all types of disabilities.

So the Supreme Court actually, so folks who were around back then, it was a little touch and go.

We were a little nervous about what the Supreme Court would actually do with this case.

a But the court wrote that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.

We're actually pretty happy with the language that came out of the Supreme Court.

The court also wrote: confinement in an institution severely diminishes the everyday life activities of individuals including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment.

This is really important.

So some of what you might have been hearing a bit about, particularly with ADAPT's work and NCIL's work on the Disability Integration Act.

Is talking about life and liberty and all of the things that we basically are assumed as values for Americans.

And how institutionalization interferes with life and liberty.

What a lot of people don't necessarily understand is life isn't defined as living.

So like being physically alive, your heart beating, that's not what the framers of the constitution were talking about in their rather skewed manner.

The courts over time have interpreted life and liberty to be things like have a home, have a family, get an education, have a career, work, worship in a religious institution.

That's life.

It's the things that make life worth living.

It is those things that is the involvement in the community, that's what the framers, that's what life means in this context.

So when we're talking about institutionalization, all right.

Do you have an opportunity to get an education, to have a career?

Do you have all of those opportunities when you're locked up in an institution?

No.

So really, it was kind of interesting having gone back just recently and read the oral arguments in Olmstead.

It was Justice Scalia who actually said, you're talking about the ADA, but couldn't you just go right back to the constitution?

There really is constitutional basis for the work we're doing, I want you to have a sense of that and what that all means and that rhetoric.

I want to acknowledge, okay, let's be clear, the people who framed the constitution and wrote the Declaration of Independence, they had a particularly skewed view of what that actually meant.

It was very limited, primarily to a specific group of folks who they were thinking about.

I'm talking to the aspirational values and expanding that.

So it's not just men, it's not just white men, it's not just white men who actually own property.

This is something that all of us should have.

And that's regardless of all of the factor, race, gender, sexual orientation, religion, immigrant status.

These are the things that are valuable to all of us, and disability needs to be included in that as well.

So challenges, there are challenges, as we've touched on, there are challenges for both individuals and organizations in doing this work.

Sometimes if you're lucky like in Michigan where you don't have a specific challenge, my folks in Rochester are still awed by that.

They are like, oh my God.

How does that, how do we not have something like they have in Michigan.

Why do our home care agencies fight with us?

But we have other things that, so there are challenges organizationally and individually.

So long term services and supports involve a lot of funding streams, it's complicated.

Administered by federal, state, and local agencies.

It's a confusing maze of organizations and bureaucratic requirements in a time of vulnerabilities and crisis.

If transition and diversion were easy, like a do it yourself project, everyone would do it and they wouldn't need our involvement, and we wouldn't be doing training on it.

But for folks who are doing this work, it's freaking complicated, right?

Yes?

Nods?

Some nods?

Usually a lot of nods.

I mean, I think in some ways, transition is easier because there's a process you can actually move through and plan for that, and you have time.

Sometimes with diversion, you need to pull all the pieces together.

You may have a critical piece of housing, but you need to pull everything else together in a very short order or the person ends up in an institution, so it can be very, the time frames can be very tight.

Coordinating systems through Aging and Disability Resource Centers, Money Follows the Person, Veteran Directed Home Care, some of these are effective in some states, and not so much in others, I think we've talked a bit about the variation among the states.

Some states have Money Follows the Person.

It's going away, other states don't have it.

There's a lot of variability.

What that means is a lot of our challenges that we face in various states are going to vary from place to place.

Some of what we've been trying to do in this work is actually take it to where we can see commonalities and themes, and actually develop skills that can transfer from state to state, but the specific pieces may not.

Federal policy is highly volatile right now, surprise.

No one has noticed that?

You're not watching anything.

In this rapidly changing environment, we must stay nimble.

I have looked for the exit personally.

I tried to find a way back to the original reality that I was living in about a year ago.

That's not happening.

So it is not just the change in the administration and the political dynamics in our country.

There has been a lot, even before that, and all of those, so there's a lot going on.

State budget crisis, who has a state that's swimming in cash?

No hands.

All right.

And long term services and supports are expensive.

That's just what they are.

So consequently, when they want to cut, they immediately look to us.

And sometimes our allies actually frame us as the problem.

So you'll see, like, stuff coming from Families USA that talks about elderly and disabled, not because the percentage is wrong, constitute only a small percentage of the Medicaid population, but they use a giant percentage of the resources.

Well, okay, that's because inoculations for children are relatively inexpensive.

Daily services and supports in the community for elderly and disabled people, really expensive.

So like looking at the cost differential, it is just not a fair thing.

But we have to recognize.

So even though home and community based services are generally less expensive, because they are optional, they tend to be the thing the that people or states want to cut, that's where they tend to go.

Managed care is expanding, as I mentioned, so are folks working with managed care companies, a few nods, a few hands.

So that has been a major flux in how things have been done.

I know in New York, we used to, everything used to be paid for through Medicaid.

It was a relatively smooth, it had its issues, but it was a smooth system.

Now we have what, at least 40 different managed care companies, all of whom have their own separate billing systems and their own tangles and their personal goal is to not pay you.

So for small, particularly for small centers, even when you're a big center, the scale of the problem just grows.

So the issue of not having money is a big issue for us.

Okay.

It helps to actually read my notes before rather than just wander through.

All right.

I'm going to jump off the slides.

Some additional background.

I want to talk, this is about where do these additional core services come from.

So when we're thinking about the fifth core service, I'm going to go back.

When ADAPT and independent living, for me, it's ADAPT and independent living really are kind of a mix.

Particularly of late we're much more mixed together than we had been even just a few years ago.

Even a year ago.

But there has always been this strong intermixing between folks who are doing ADAPT work and folks who are doing independent living work.

So when we were going through and we had secured a good decision in Olmstead, those of us who were looking at the situation, there were more than a million people in institutions.

Having a Supreme Court decision was great, but let's be real.

A Supreme Court decision wasn't going to get one person out of, maybe it got a couple people out of an institution, but it was not going to move or support moving more than a million people where they wanted to go.

For that, you actually needed a system.

You needed, quote, providers.

Now, a lot of folks in independent living may not consider ourselves like a provider network, but what we were doing was strategically, we were looking, there needed to be people who went into facilities and helped people get out.

That was a real critical piece.

So when we were thinking through who could do this work, because back then there wasn't anyone, quote, officially doing this work, we started to think through what did we need to do this?

So first off, they needed to not be a part of the institution.

Cause frankly, the fox is not a good person to guard the hen house, as I have recently experienced.

It was, it was a coyote, and believe it or not, I am at the intersection of queer man and chicken farmer.

It's a weird place to be.

But the thing is, the institution, the social workers in the institution sometimes are really pushed to maintain the beds that they have.

They are not going to be people who can do this work.

So we needed someplace that was not a part of the process or the places that kept people up.

We needed something that was national, right?

We needed a network that was national that could support people transitioning in the community.

So it would be great, you know, okay, so maybe folks in Texas and New York were talking about it and we had this great idea and we would use a group that was only in Texas and New York.

There are a whole bunch of other states and territories that need to actually have services and supports to help people out as well.

So it needed to be someplace across the board.

We were thinking it needs to relate to the mission of the group that's going to do this because, frankly, people aren't going to go way off of their mission.

So if we're looking at the developmental disability provider network, not so much.

So supporting people, older individuals, people with significant disabilities living in the community, they probably weren't going to be a network that would be one we could easily leverage in doing this work.

So one of the other things we were thinking about is who is already doing or at least doing the work of transition?

So this is back when we were looking at how to get folks out.

Or at least some components of that, because there needed to be some level of expertise and involvement that folks had in terms of doing this work.

Who is strong enough to push back against the institutional bias and ableism?

So at the end of the day, when you're dealing with, as we have talked about, some of the structural problems, like what was interesting is, when we started doing transition work, all of these ombudsman folks would come to me and say, you know, there's this 20 something young man who is a quadriplegic, he's really appropriate for community integration, but all of these other people, not so much.

Or they would look at someone with a very significant disability and say, I'm not so sure, you know he uses a ventilator.

I don't know that he would be safe, and that whole issue of safety and risk.

So we needed a group that would actually push back against the institutional bias that really sweeps people into the institution and would actually recognize, calling it out as ableism, that issue of devaluing the lives and independence of people with disabilities.

We needed a group that had the ability to share technical information and expertise across it.

So there had to be a back end that could provide the training and support to the folks around the country.

And we needed a group that was actually going to be able to do this with virtually no money.

All right.

At least as a starting point.

All right.

So I'm serious.

Now, you're thinking, well, he just described centers for independent living, right?

for independent living, right?

I can't say whether, you know, it was kind of organic how this process evolved to getting to a fifth core service.

Was there an ah ha moment.

I can't actually think of this ah ha moment when it actually happened or whether it was just a building consensus that grew.

It's sort of like we didn't find the one.

We just realized we were with the person we needed to be with all along, and we just needed to call it out that way.

That's probably how I see it happening.

But there really was a strategic conversation.

We have the law.

We now need a network of folks to do that.

So having gone through that list, can you all think of another group that would actually have met that criteria?

I'm seeing not so much.

Okay.

I can't either.

Now, even now, you could argue potentially the triple As, the Area Agencies on Aging might be a network that we would leverage, but even so, they tended to be not, there were issues sometimes I find with ableism within that group, the triple As, the Area Agencies on Aging tend to not be older people themselves, but to be younger service providers, so they tend to get caught up in some of that.

I think they are there, but that really wasn't the network we were looking to leverage, although we did actually have some conversations.

So now you're thinking he talked about doing this with no freaking money.

I feel like we've just been sold a bad bill of goods.

The strategy isn't over.

The first step really was to identify a network that we could build on to establish transition and diversion as a role within that network, and then the next stage of this is to develop the funding streams to support that work.

Because our understanding is, when you look at the development of the Developmental Disability Network, they had the network first and then the network and the community were able to advocate for the funding.

So we're at that middle point now where we're trying to sort through the issues of what does this fifth core service mean, I take no credit for actually defining it this way, although I will take some of the blame for having it, we will talk about this later, defined as a service as opposed to an outcome.

But we didn't actually have, you know, four core outcomes, we had four core services.

So I will take some of the, I was a part of those conversations.

But I just want us to all have a sense, this actually is part of a plan, a larger plan to actually support the independence and integration of people with disabilities.

So now we have centers are now on record as being the only organizations mandated to provide transition and diversion.

That's really important.

We're the only group in the country that is mandated to do this work.

hat means we are unique in that service delivery model.

We can use this as leverage.

So we can look at maybe contracting with managed care companies and such to try to actually fund this service, we're looking at how we can actually move federal dollars to support the funding for this service.

But having a network that actually is charged with doing this work and is unique is actually an important part of that.

The ADA and the Olmstead decision still are a legal framework.

So when we are doing this work, so as we talk about sometimes when we get push back, we can use that as leverage to support the work that we're doing.

But we need to be at the right tables.

So we need to be talking about this to make this all happen.

I think that is some of what we're doing here in the next couple days is really trying to define and clarify what it means to do diversion work within this context.

We all know what transition is, but how do we define diversion?

And how can we make the case for what we're doing?

So it will be really important.

So I want us to have a sense of, okay, I have been doing this issue for 27ish years, sadly.

Actually, I've enjoyed the 27 years of doing this work.

We're not all the way through the process, so this is really generational change that we are trying to change a big system is generational, which is what we're trying to do.

So what we need to think about is what can we be doing now to actually lay the ground work for the next level.

I think some of the conversations we're going to move into in terms of is this an outcome, what counts, how do we present it?

How do we report it?

All of this is not a conversation from my perspective to support the Administration on Community Living, ACL and the federal government and their regulations.

They are important, but that's not where I personally or we collectively are trying to go.

What we need to do is figure out how to make the case for us to be funded.

And to support this work.

Because, frankly, a couple hundred thousand dollars is not going to support us transitioning massive numbers of people.

When people with disabilities ask folks in institutions who want to get out, 60% of them say, yes, I want to return to the community and virtually everyone who is in the community says they want to stay.

That's a whole lot of people who need services and supports.

And we're the only network that's charged with doing it.

I just want to throw in one other piece here for us to think about in terms of when we are moving forward and how we frame some of this.

For our center, we strive to represent, to hire the people who are representative of our community.

Now, why is that?

Okay.

Intuitively, people who are from a community know how to talk to each other.

Okay.

Let's take it outside of typical diversity and think about the National Organization for Women.

This is one of my favorite examples.

If the National Organization for Women were run by a group of men, it probably would have a somewhat different agenda.

Right?

There's a lot of women here.

Right?

I see some, yes.

I could not hear.

AUDIENCE MEMBER: I'm the Iowa NOW state president.

BRUCE DARLING: Okay.

Well, more power to you.

Gender is more fluid nowadays, and I don't know what's, I can't speak.

Okay.

Trust me, I understand fabulous.

But the issue is, I think what we try to do is make the case, and it's real.

So from my personal perspective, I'm a queer man.

As much as I am assimilated and work within the straight community, sometimes when I'm talking about my life and what I need to deal with, it's really, it resonates different with other people who live the life.

I think we understand this generally speaking.

We don't, so people of color, okay, reality check.

If you are not trying to hire people of color in your center to be working with people of color, get on the band wagon and figure that out, because you need to do that.

Diversity means we are different and we need to find people who are like us and can talk to us.

I think we're missing the boat in not framing disability in that context.

Because frankly, and this is not just under number 45, this goes back into the prior administration, there was a lot of talk about we moved from understanding that diversity included not just people of color, immigrants and all of that, we actually moved a half step to understand LGBTQ folks, but disability was consistently framed as broken versions of other people.

So we were seen as broken versions and not recognized as a community who understood each other in a unique way.

This does not mean we, diversity comes on multiple axis and we need to actually be addressing that internal to us.

But I want us to think about how as we're moving forward particularly in conversations with managed care companies and with other folks, that we are unique in that we are providing services and supports to people with disabilities by people with disabilities.

We understand each other and we can actually move forward together that way.

So any questions?

Comments?

AUDIENCE MEMBER: One thing that hit me while you were talking was, and I do this myself.

Oftentimes I make excuses, yes, it's a core service, we are charged, we're the only group that is charged to do this, but it's really easy to say, but we don't have any money, so we can't do it.

That's not going to give us the credibility.

And that was just a light bulb that came on.

I have to quite saying that.

BRUCE DARLING: And honestly we are doing it, it is a matter of let's take credit for the work that we're doing, count it, highlight it and actually market that and make sure.

Because that is the first step.

Instead of saying we can't do it, we are doing it, but we're just doing a small piece of the work that's there.

The funds need to come to support all the work.

And that's how other networks have built theirs.

Anything else?

All right.

With this, I will turn it over.