BRUCE DARLING: All right.

So you guys are the hard core people who decided to stay.

I appreciate it.

Thank you so much.

Before we start, there have been a couple of things that have come up across the last couple days that I just wanted to sort of.

It's a bit off topic, but indulge me.

So the comment that was made about housing, we can yell and scream, dot dot dot.

That really resonated with me.

Because honestly, we can yell and scream, and honestly you can throw and handcuff yourself to something, get arrested, and it seems like you can't move some of these pieces.

In some states, we are looking at the budget situations, the availability of services and supports.

15 hours a week, okay, let's think about what that translates into.

We clearly are preventing people with very significant disabilities from living in the community.

I would like to draw your attention to the Disability Integration Act and remind you that we are working on federal legislation that would address some of these issues.

In relation to the housing.

So basically, DIA is civil rights legislation, it is not in Medicaid.

It says that people with long-term service and support disabilities have a right to be in the community, if they could lock you up in an institution, they should provide you those services and supports in the community.

But it also addresses housing.

There's a prohibition in the bill, easy for me to say.

That says, for the purposes of this Act, discrimination by a public entity, meaning state, also includes a failure to ensure that there is sufficient availability of affordable, accessible, and integrated housing to allow an individual with an LTSS disability to choose to live in the community and lead an independent life including the availability of an option to live in housing where the receipt of LTSS is not tied to tenancy.

So basically what this legislation would do is say if your state is not providing sufficient LTSS or providing sufficient housing for people to be integrated in the community, they're breaking federal law.

Not only can they face federal action, individuals can sue and seek punitive damages.

The interesting thing about this is we had at least four republicans on this bill.

So I just want you to have a sense of there are a variety of strategies that we're trying to use to address these issues.

So the individual grind that we have that we're doing to try to expand the availability of these services is one side, but we're also working to put pressure on the system from other angles as well.

That's important because we can do this in terms of the housing piece, but we can use this also in terms of how we all work to secure funding.

When we were talking, what was interesting, is folks talk a lot about, the thing I love about IL is we are resourceful people.

People who don't have anything can find stuff everywhere and we celebrate the things that we find.

So I was hearing, there's this resource and that resource.

But how many folks feel like they have enough money for the basic thing of staff?

Anyone?

Not so much.

So really, what I'm going to focus on, trust me, you just never do.

The need here is so great there probably isn't in my lifetime going to be sufficient funds.

Maybe.

We'll see.

But the work we're going to do to try to find pieces that can build up to support the work that we need to do, the staffing levels that we need to accomplish the work is where we're going.

So potential funding streams to support diversion work.

There's a whole bunch of stuff under Medicaid that can support diversion work.

Home and community based services waivers.

So we talked about those a bit yesterday.

Targeted case management.

I will go into each of these.

Other Medicaid services including behavioral health services that may be funded through an 1115 demonstration waiver.

Contracts with managed care organizations.

Other state contracts.

I'm highlighting something that we've seen in a couple states called managed care ombuds program.

Establishing private pay services and grant or foundation funding.

This is my little list of places that we could potentially get these funds.

I'm sure there are going to be others that folks may be able to come up with.

So starting with Medicaid home and community based services, or HCBS waivers.

So how many folks are engaged as providers under waiver services, the centers?

I don't know, less than a quarter of us.

So for the folks who are not.

What you're going to need to do is figure out where these dollars are.

What they do is, they fund services that support, these waivers fund services that support, oh, my God, bad typing.

Support services as an alternative to institutional placement.

So anyone who gets these services, must meet the level of care for an institution.

So HCBS waivers typically are for people who are at an institutional level of care.

So we think of them, one of the first waivers we had in New York was called the nursing home without walls waiver.

Or the Lombardi program.

It was not well named.

It was one of the first ones, so they had some issues.

They may be targeted to specific groups of people with disabilities or multiple groups may now be combined.

So what you typically see is you have a developmental disability waiver, maybe children with mental health disability waiver, an aging and physical disability waiver, or a multitude of these in your state.

You may have a bunch of them.

Your center can be a provider for those.

It had typically been when they developed these that you had to serve everyone under a single waiver or under multiple waivers.

Now the states actually have the option to combine and mix populations in these.

When your states are talking about, well, it is too complicated to do all of this, there's so many waivers.

They don't have to have so many waivers, they could actually consolidate these things and still use the same funding stream.

Services and supports may include some type of care coordination, service coordination, case management.

Andrea, what was the one they use here in Georgia that was news to me yesterday?

Do you remember?

Support coordination.

So theres, that can be a lot of names for it, but that kind of person who handles the planning and monitoring.

It may include in home or community based supports, like the people who do the direct assistance with folks, and a wide array of other things.

I've seen home modifications, vehicle modifications, peer support has been included as a waiver service.

Independent living skills training, community integration counseling.

So there's a whole array.

Basically, you are not, states aren't limited to a check box of existing services.

So just because it doesn't already exist doesn't mean it can't exist.

They have a lot of flexibility.

It's important for you to think about what you're doing and how it could be potentially incorporated in these.

These and similar services may be provided under a number of Medicaid authorities.

So what it means is, so I'm talking typically about what's called 1915C, you'll get into is it an I, K, B, all these letters, blah, blah, blah.

You probably don't care about that right now.

The issue is really, know that these kinds of things can be done for folks who are at the institutional level.

Services can be provided in the community.

If you're engaged in that, great.

Power to you.

There's dollars there.

If you're not, try to figure out where the waivers are that you could be fitting yourself in, and becoming a provider.

The fact that maybe a quarter of us, 20% are already doing this means that within the network there are resources, people you can talk to who are doing this kind of work and who can be helpful to you.

Now, I know being in a state sometimes if you call another center in your state, they might think you're trying to get into their territory if they're already doing it.

So that may or may not be a resource, but there are other people who know this information and can help you too.

So if you run into a wall, this is one possibility.

Questions?

Questions on waiver services?

Thank you, Tim.

Okay.

Medicaid or targeted Medicaid case management.

So this is different from waivers.

So this is a lot, there is a lot more flexibility here.

Medicaid case management facilitates access to needed services through, these are actually really important.

These are required components of case management: Comprehensive assessment, care planning, referral to services and monitoring.

When I was talking about all those calls I was getting, my ramp was taken by the church people, I pushed my girlfriend in front of a van, she's at the hospital, this was what was funding those.

That was considered monitoring, assessment care planning, referral to services, because think about it.

Isn't that what we already do?

So it was very natural to sort of do that work in a Medicaid fee for service system, because we were already doing it.

Case management services provided only, can be provided only to specific classes of individuals or to individuals who reside in specific areas of the state or both.

What you didn't hear here is it's only for people who are at the institutional level, right?

It can be any group of Medicaid recipients who need this type of case management.

That would mean, so folks who may not be at the institution, your state could actually target these services to folks who are not at the institutional level, who may be at risk of going into a nursing facility down the road.

It could be a very valuable tool for centers to do outreach, to do diversion work.

This is one of the things we could do this with.

It says that there, could be used to fund institutional transition and diversion services.

Services are billed to Medicaid.

So recipients must have Medicaid.

I know that not any of these funding streams solves all of your problems.

But when you begin to build them together, collectively you can begin sort of a financial portfolio that begins to serve a broader group of folks in dealing with your IL funds.

Any folks know if they're doing targeted Medicaid case management?

Through their centers.

You used to, Jim?

So we use, oh, good, Maureen.

We've got some folks, any advice or suggestions to folks on that or want to share about what you're doing in your states?

You don't have to.

Maureen hesitated.

AUDIENCE MEMBER: It changed a lot in the last year.

We do, are doing this now through managed care as of August 1st.

So we're really trying to get a sense of how it's going to be perceived by the six managed care companies that are under contract.

But the targeted case management has been elderly targeted case management and targeted case management for people with DD.

And then we have of course transition coordination through Money Follows the Person, which is different.

It really hasn't been a medical model.

It's been pretty good, primarily because it started through the centers, and the centers made it what it was.

We were kind of lucky in that way.

We are anxious about being administered differently now, but hopefully we've been able to establish a good base and can maintain that.

So it's basically monthly case management, pay to fee monthly.

You see individuals as often as you need to, but no less than every 90 days, but every state is going to set their own parameters for the scope of that service.

BRUCE DARLING: And you can actually.

States have a lot of flexibility.

When I started doing targeted case management, I think we were paid $7.58 for every unit of service, which was a 15 minute unit.

So from seven to 15 minutes of time constituted a unit.

We got like seven bucks for each of those.

Given the stories, the series of calls that I got, you can imagine a small group of people turned into a lot of units of service, simply because of the things that were going on.

This is a potential resource that centers could take advantage of.

1115 waivers.

1115 demonstration waivers, you might have some bad feelings about these, because typically they're used to muck up services, but they give states additional flexibility to design and improve their programs.

They demonstrate and evaluate policy approaches such as providing services not typically covered by Medicaid and using innovative service delivery systems that improve care, increase efficiency and reduce costs .

They have been used to undercut traditional Medicaid services, but can also be a powerful tool to improve Medicaid and create new services.

So the thing about an 1115 waiver, is basically you can do almost anything with it.

When you're looking at what the authority is, it talks about using innovative service delivery systems that improve care, increase efficiency and reduce costs.

I don't know, I think we're pretty innovative as a group.

So the thing is, typically these waivers are instituted through negotiations with the high power Medicaid folks in your state.

There's a lot of stuff around hospitals and all of those pieces.

The big players tend to get big pieces of this.

But it is a tool that we can also either take advantage of and get involved in those networks or we can actually help build them ourselves.

Anyone doing any work?

1115s can be used, some of the work that we're doing in managed care is actually under an 1115 waiver.

Just because it says it's a demonstration and it's supposed to be a demonstration, sometimes these what are considered demonstrations actually become long-term ways the states do these services using 1115s.

So Maureen is ahead of the curve on this one.

Contract with managed care organizations.

CILs can contract with MCOs to provide member services that were previously paid for directly by Medicaid.

CILs have contracted to provide home care and consumer directed assistance services.

MCOs may also contract for additional services that help improve outcomes and reduce costs from unnecessary hospital admissions, hospital readmissions or institutional placement.

So thinking the things that cost them money.

CILs have successfully negotiated for enhanced funding in recognition of the value added services provided by the center.

A good example of that is Topeka Independent Living, negotiated a higher rate with the managed care company for some of the wrap around services that they were able to provide in the waiver services that they were providing through the MCO.

Sometimes the approach of negotiating with the services this has not been a successful model for us in New York.

The MCO has been more inclined to cut our rate and say, suck it up, you're in the system or refuse the rate and you're out.

But this can be, there are models out there where you can actually get embedded where you're talking about ways that you can reduce costs where you can make things more efficient for them that they are willing to pay for that.

Any folks other folks?

AUDIENCE MEMBER: I would just caution on that.

At least, our experience in San Diego with a managed care organization is that they wouldn't accept a contract from us where we said that the individual had to kind of be on board with the CIL philosophy and consumer driven and that kind of thing.

It was very difficult to get that written into the contract language and very difficult for us to deny referrals of folks that didn't want to be a part of that.

Obviously we should be working to bring these folks in, there are people with disabilities and that type of thing, but there are just going to be those people that a CIL is not the right place for them.

And at least the managed care organization that we work with, are like, yeah, you still are to work with them, have you a contract with us, and if you're using your CIL funding to kind of bolster this program because they don't pay us enough to like fund a staff person.

How do you justify using your IL funding when the folks that they're referring to you aren't necessarily right for IL.

So I think that's been a concern for us with managed care.

BRUCE DARLING: Okay, so.

The comment about how do you use your IL funding.

That's a great comment, because I sort of came to a similar position from a different reason.

I was feeling like so you're expecting me to sub, you are a multimillion dollar managed care company and you're expecting me to subsidize your services with my money, which is not so much, actually.

At the end of the day.

Those negotiations can be very tough.

It put me in a bind, because, really the issue for us was on our consumer directed side.

I wanted attendants to be paid well.

So we were basically subsidizing the rates that were going out to the attendants, and could not continue to do that.

And basically we were also told that we couldn't discuss our rate that the MCO paid us, because they didn't want us to encourage people to say, you know, if you go over to that MCO, there's more money coming in.

So we tried to think of what is water around the rock.

How could we get to a place where we could solve this problem?

We created different pay scales for each of the MCOs.

They're directly tied to the rates.

It is formulaic.

But basically, and we were not telling people what the MCO was giving us, we were telling them what's available to their attendants.

And people talk, so people begin to share information and that approach actually put the disabled individual in the position of being able to make an informed choice about where they were going and pulled us out of the mix of basically trying to subsidize the MCO.

The contracting process of what you're willing to do and what they're willing to pay for is something you are going to have to negotiate through.

The other caution is, will they give you the money after you've done the work.

It is really something that you have to make sure you can actually get to those dollars.

Other state contracts.

So this is a fun one.

So there's any of a variety of things that your state would contract for.

But some states have contracted with organizations or networks of organizations to serve as advocates for individuals enrolled in Medicaid managed care.

It's been funded by a fee placed on the MCOs, it's then distributed as a state grant.

If your state is implementing managed care or renewing federal approval, you may want to advocate for this approach.

You're probably wondering why is it a fee on the managed care company that comes back to a grant.

Basically that's the state's way of laundering federal funds.

They bill Medicaid for the money that goes to the MCO.

They charge a fee, then they use the fee to do this ombuds program.

The model for this came out of Wisconsin, we mirrored it in New York.

We were so excited about it we actually agreed and believe it or not the state, I can't believe they did this, the state let us right the RFP for them.

Our agreement had to be we wouldn't compete for the funds, because we had access to it.

But we helped write the RFP.

We gave them the drafts all up front and created a statewide ombuds program.

So that means, individuals who are having trouble with the MCOs, which we're all familiar exist, have a place to go who could advocate for them.

Centers are a part that network.

We're not because we took ourselves out of the mix, but it is a vital piece to that.

Now you're thinking why the hell would the state want to do this.

Really their goal was it begins to pull back some of the criticism if they have a system to address some of these issues.

They can't be as criticized for managed care cutting services.

But think about that as who does this kind of work, we do.

So this is an area that if your state has a network like this you can potentially dove tail in.

We'll talk about how you might get one.

Other state contracts, actually, anyone else have interesting state contracts that would support diversion work?

There's always sort of.

Okay.

Establishing private pay services.

I'm sorry.

Jim?

AUDIENCE MEMBER: I know the veteran's administration is not part of an MCO, but they're sort of like an MCO.

I am just wondering if there is anybody out there anywhere that has been successful in getting contracts with the VA system?

BRUCE DARLING: That is a great, anyone?

There are people, anyone in this room?

Thank you.

AUDIENCE MEMBER: We do currently.

We work with the veterans department.

We do contract out and we also have another department in regards to the veterans.

But we do, one of our programs is strictly from the VA.

We do have that in Michigan.

BRUCE DARLING: Cool.

Establishing private pay services.

NCIL has a veteran subcommittee that does work on these issues, although I don't know the information, I can connect you with the people who do, because they do a lot of work around the VA, it's a hard working subcommittee.

So if you'll e-mail me, I will connect you up with that.

Private pay services.

Some CILs have developed private pay options for different services.

We can apply this model to support our diversion work.

We've done this in a variety.

When I started in IL I was an architectural barrier consultant who would measure toilets and churches and give them recommendations and we would get a little money.

Depending on my effectiveness at actually sending that information up so money would come in.

I was 20.

I didn't realize actually that money was as important as it is.

Now I understand why my boss was sometimes frustrated with me.

So we have done this in certain areas.

CILs have some experience in doing fee for service.

Doing it with diversion work builds on the expertise CILs already have.

We can identify gaps in the system where people need more intensive information, advocacy and support.

I know there's a wealth of stuff out there in terms of services and supports around diversion.

There's the ADRCs and all of the multiple groups out there.

Look at the gaps and where people need something more than is already there.

Although individuals may not have the fund to pay for these services, families may have the funds and recognize the need for diversion support services.

I was looking at some of the services that are available.

The aging organizations have gotten pretty good at doing some of this.

Locally one of the aging organizations, as a fee, provides peace of mind planning services.

These are specific, I thought it was kind of interesting.

It was specifically what's going to happen when your spouse dies?

Do you know where all the bills are?

Do you know all the passwords?

All of these are the things that you need set up if one of you dies.

Or if your parent is going to die.

Who is going to help you figure this all out and make sure you've covered all your basis?

Life span is going to do that.

There is a fee, but peace of mind is worth the small fee that this service offers.

Now what is interesting to me what I would probably have done is write up some information and we would have treated it like a little handout kind of thing that was hanging out in the front lobby.

We would have just given it away freely.

These people have turned this into a resource.

We may feel like we're selling our soul, actually, we're bringing money into the center.

I am not sure that this individual service does this.

But this is just one of an array of services.

It was pointed out to me that child care, corporate child care started because people were having issues with attendance at work because they were taking care, they were having issues taking care of their children.

With the shift in population, I suspect that we're seeing similar dynamics with helping with your elderly parent, this is an area we could also reach out and look at whether we're contracting with corporations or companies to pay for some of these services.

Grant or foundation funding.

You can hire a grant writer.

Pay for one under contract or do it yourself or secure a volunteer.

We have done all of those.

Some are more successful for me than others.

If you need help with this or know a CIL outside your area that has had a similar proposal funded, they may share some or all of their written proposal with you.

You can offer to pay them out of the successful proposal for technical assistance.

Actually, I was talking to Michelle about with the survey.

I was recommending that she reach out to some academics who might want to do this.

I was thinking, they might actually figure they get a grant to do some additional research, validate this, work on her project and throw some money back at the center for the work that was already done.

Probably a secret, Center for Disability Rights, was started in this very way.

I reached out to a center that had been successfully funded.

They had done a proposal.

I didn't know how to write a proposal to fund a CIL, but they clearly had and they actually provided me a great deal of information that gave me what I needed to do to be successfully funded.

This is an option.

Although foundations don't generally provide ongoing support, you can develop an ongoing relationship and fund various projects over time.

This is not necessarily good ongoing funding to support staff, but it can be seed funding or those types of things.

So strategies to secure funding in your state.

Individual CILs can seek contracts and funding under any these existing funding, if you have these things, you can seek funding under them.

But we can also work together to develop new funding opportunities as well.

I like that I have this slide here Maureen to prove that I was not stealing your idea.

When I was listening to Maureen talk about how the centers worked together, it wasn't just that the centers were lucky.

They were fortunate that people listened.

But it started with people working together and pitching and moving the idea forward.

CILs in a state can work together to create new funding streams that support diversion services.

So that list of things that I was going through, HCBS waivers targeted case management, those types of things.

That was meant, I know a lot of folks may not have those, but those are options that you have to actually do that to create the funding streams to support the work.

CILs may want to identify other partners or dove tail this work into existing efforts in their states.

Like when the hospitals are doing a big push for a big an 1115 waiver, if you can get into that mix and become a part of their push and have a component that goes to peer services and peer supports, you might be able to secure funding for your state network that way.

I suggest consider utilizing the statewide independent living council as a mechanism to develop policy and build state IL capacity.

We did this very effectively with transition.

So many centers do transition.

Why are we all doing this?

Because we were using the IL council's ILRU.

We were sharing the technical assistance just like we are doing here with diversion.

We are building the technical skills and the capacity for us to do this work.

Use that and not on this slide is consider using an ADAPT Chapter to push from the outside.

So one of the great things is when you have a state council that's issuing a report calling for a need, outside agitators pushing to address the need and a very supportive group of organizations that are willing to do the work, you can actually move a lot, and that has been the model that we have used in New York.

So the SILC, ADAPT, the centers as an association have all worked together.

That's how we created the nursing facility transition and diversion waiver in New York.

Strategies to secure national funding.

National efforts are being developed through NCIL to adequately fund CILs to do transition services.

IL funding is a, not a, it is the top priority for NCIL.

Probably a bad choice of words.

It is work done through the Rehab Act Subcommittee.

One of the things for folks who go to NCIL, it's always the top priority, because honestly, we do need funding, but NCIL is also engaged in conversations with ACL about the next generation of Money Follows the Person, MFP, which acknowledges the CIL's unique position in regard to the new fifth core service.

I put that in quotes, because we called it a service.

Tim?

TIM FUCHS: I think this is funny.

I didn't know you had this slide.

I made a note.

I wanted to mention before we finished that NCIL, we have the capacity to build relationships with foundations and funders, one thing that's a big priority for us lately is to find pass through grants that we can share with the centers.

We have the relationship, we develop the program, and then through an RFP or through relationships we put those out.

Right now in fact, there are a number of centers in the room that are a part of the project with the Craig Nielson Foundation.

This is year two, but this project is specifically regarding transition and diversion, which they were really excited about.

So Ability360, LINK, and Boise, IndependenceFirst in Milwaukee, Houston Center for Independent Living, Center for Disability Rights in Rochester, and Independent Living Resource Center in San Francisco all are a part of that project.

That is something else to, that we will continue to try to leverage our relationships to try to do that.

That's a member program.

You have to be a member of NCIL.

It more than will pay for your dues if you're able to get one of these grants.

We do this with a number of groups.

We have been talking with Craig Nielson and I just, I stole Steve Gold's words from like 20 years ago about closing the front door of the institution, they were like, that's revolutionary, oh, my God.

You can get funders really excited about this stuff.

Just look for that.

BRUCE DARLING: Thank you, Tim.

So with the conversations with ACL, so we know that, so there's been some push to actually just re-up Money Follows the Person as is, get it refunded.

We see variation among the states in terms of someplace it's worked, some places it doesn't.

If you think back to the beginning when I talked about how the overall strategy was create the network and then bring the funding in to pay for the service.

We are on target to do that, the fact that we have structurally centers positioned to do transition and diversion means that we can actually talk about redirecting MFP as a funding stream through the center network to do this work as opposed to having states just go and do whatever the hell they're doing in some places.

And that includes New York.

Again, if your center is not a member of NCIL, please consider joining, I would be remiss if I didn't say that.

Key considerations, I think this is the last slide, so I'm good, Tim.

Dollars make sense to policy makers, so advocating for new funding streams, advocacy for new funding streams will need to demonstrate how they can result in overall savings.

We can focus on unnecessary hospitalizations, hospital readmissions, and institutional placement.

I keep saying those things because everyone is talking about these in the health care field.

That's where the savings are now.

So we need to make sure we're a part of that.

A good story won't win over the state's budget office, but I can tell you, we will need numbers and hard data to make the case.

You can win over the state budget office with good financial projections.

I'm very proud to have gone into the New York state budget office with a proposal on a series of proposals to improve transition in New York.

We showed them how they could save a billion dollars across I think it was over 10 years, We had it broken down by quarter across the 10 years and the budget director said no one has ever come into this office with a proposal so well thought out and so well defendable.

It's the best analysis we've ever seen.

So thinking that through, how is this going to work, we do need the data.

So again, I thank Michelle for coming up with the survey that helps us look at at risk, because that will allow us to drill down, pull good stories together and good data.

I am encouraging everyone to use the expanded cultural competence argument that brings disability diversity while ensuring your organization demonstrates more traditional forms of cultural competence and diversity.

What I'm saying is don't acquire and use the language, without walking the other walk.

But it is important.

I think one of the things that we can do is we are not selling ourselves in that way.

And it may not be the environment right now for us to be making those arguments with some people in some places, but this conversation about diversity, cultural competence and the fact that people with disabilities talking to people with disabilities is important, that resonates in other communities and helps build some sort of bridges across.

All right.

Any questions, comments, other funding streams?

The veterans was great piece, Jim.

I had not put that on my list.

Okay.

TIM FUCHS: Thanks, great job, Bruce.