PAULA McELWEE: All right.

We're going to talk a little about the law and regulations, because we have some new ones in addition to the great stuff that Bruce talked to you about that are already existing and have been for some time, we have some fairly new regulations that are happening.

We also have in a lot of states, either a change in your Designated State Entity or your, or a change in their responsibilities, which happened kind of across the board when we changed them from DSUs, units, to DSEs, entities, in the law, the regulations that support that change did as well.

Yeah.

There we go.

So when we talk about the law, one of the things that we need to remember is every state is different.

And there are some things that states can impose that are different from what the next state does.

So you have to know those things.

We'll come here and we'll tell you all the things that we can think of.

You'll use your different examples.

Maybe you can go back in and change at the state level some things, like how your waiver is written or ways that things are being interpreted.

Sometimes it's going to be a state issue.

That is kind of out there like a cloud for all of us to deal with, and we can't deal with all of the variances here, except strategies for change.

Because strategies for change are what we're going to do in order to make that happen.

But the state law is kind of over everything else or has a cloud over everything else and can tweak or change the different things that we do state to state.

The law we're talking about here is the Rehabilitation Act.

So Bruce talked to you about a couple of other laws that apply.

But the Rehabilitation Act applies to centers specifically, what are centers supposed to do?

So there's Title VII of the Rehabilitation Act, and sometimes we just call it the Act.

Because it's the one.

But we have others, but it's the Rehabilitation Act.

The most recent regulations related to that are found in the Code of Federal Regulations and the code is 45 CFR 1329.

Get that reference in your head, because sometimes you're going to need to go back there and see exactly what does it say, because these are the things that you will be probably at some point in the future they will look at your center to see if you're meeting regulations, so there's some kind of a review process will eventually happen, I think, from our new people at ILA.

ILA is the Independent Living Administration, and that's within ACL.

A lot of times we use ACL and ILA interchangeably, but ILA is actually our department where are program officers work and you've all got one of those for your state.

If you don't know who it is, talk to me and we'll show you where you can find that information, but there's also then your Designated State Entity within your state, and they have a lot of influence over how you can do things.

They are going to be involved in helping you to sort out any time you think that you're in a situation where their funding might not pay for it, you may need to think about other sources of fund development or resource development that might help your center.

The Uniform Administrative Requirements also are an under pinning of this, a lot of people heard them called Uniform Guidance, UG.

For a while, it was called the Super Circular.

This is the Health and Human Services Department's Super Circular put into our part of the regulation, it's also found at 45 CFR 75.

This is what you may and may not do with money.

It has to do with spending federal dollars specifically.

There are similar references in any specific department that you work with.

So you might at some point want to look at those specific references, this is the one that applies specifically to independent living.

And then there are also your own policies and procedures.

Right?

Those of course are the easiest to change of all of these, but we have changed all of these.

When the need arises, we come together pretty well as a group and we figure out what the change needs to be and we, sometimes it takes a little time, but we work towards that change together, and that's one of the things you want to keep in mind.

Also specific policies and procedures that you have are often in keeping with that whole pyramid that we just looked at.

So your policies and procedures are how you do it on the ground at your center, but it has to do with, it flows out of all the rest of these regulations as you look at them.

So the language in the Rehabilitation Act actually in this federal statute, the language when it's written into the law isn't something that the regulations are supposed to change.

And we got quite a bit written into the law itself.

So a lot of the language in the law came from us, and I think we sometimes forget how involved advocates from independent living are in these kinds of things, but there was a lot of involvement from a lot of people.

NCIL has had a long standing Rehabilitation Act Committee that has continually worked on new language and interpretations around how it affects us as centers.

So, you know, we have met the enemy and the enemy is us?

What's that phrase?

But sometimes we start picking at the language and we forget, hey wait a minute.

Let's look at that again, because it came from our advocates, most of the language here has a history within the movement and a purpose within the movement that you want to look at.

So where the regulations speak, typically they are interpreting the Rehabilitation Act.

Sometimes they're almost word for word the same.

But sometimes they expand on it a little bit to give you more information about how you might actually implement that specific part of the law.

And then if the regulations, if the law and the regulations haven't been clear enough, we can ask for more clarity, and we do that and sometimes we'll get FAQs, sometimes we'll get written guidance, sometimes we'll get a memo.

All those things are ways in which the law is interpreted through the regulations, through the additional comments that come from the ACL or ILA folks at Health and Human Services who oversee the money that comes to all of us as we go along.

And that includes the definition of the core services, the definition of the core services is in the law.

It is also in the regulations, the regulation reference is on the bottom of your page here on 19.

Independent living core services, I think we have probably have known the four core services for a long time, any of us who have been around a long time.

Information and referral, independent living skills training, peer counseling including cross disability peer counseling, and individual and advocacy services.

I want to say just one thing about these long standing required services.

I get a chance to go a lot of different places and talk to a lot of different centers.

You don't all do them the same way.

Now, you might think, we all do the same four core services, now it's five.

We all do the same four core services, no, we all think these principles are important to offer, but we individualize them to where we're from, and how our state works and whether we're rural or urban, and how the, how strong is your disability community?

And is that the first place you need to work is to strengthen that disability community?

So even the existing, long existing services are not identical from one place to the next.

And one of the things we are going to find as we talk more about this new core service, as we go through this the next couple days is that it's not the same in how you're interpreting it from one to the other.

Don't let that scare you.

Don't say, oh, no, is that what I was supposed to do?

I didn't do it that way?

No.

We're all figuring it out and we're going to figure it out together, and you may be doing something that I haven't thought of and I'm going to say, oh, wow, is that a great idea, we're going to take that home.

And then somebody else might say something and you'd say, that's never going to work where I live.

But maybe if I adjusted it this way.

We're here for the purpose of sharing something and we will not all out go out of here with the same plan for implementing it.

That's okay.

Because we're going to take these important principles and we are going to apply them in a way that is going to make sense at home.

So we're going to kind of just keep that in mind.

Speaking of the new core service, I will read it.

Services that facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community based residences with requisite supports and services, this process may include providing services and supports that a consumer identifies are needed to move that person from an institutional setting to a community based setting, including systems advocacy required for the individual to move to a home of his or her choosing.

Did you hear all that independent living rich language in there?

If you think that somebody just opposed these regulations, really and truly we had some influence on these.

They came out for comment, there was a lot of great comment from the field, never stop commenting on the things that come around that are important.

We have got to be a part of that process, you can see that language all the way through, right?

Facilitate the transition.

We're not just going to make it happen, we're going to work with the person to facilitate it.

You can see community based.

You see other institutions, not just nursing homes up there, and so far, that is left up to us, I will get to that in just a second.

But what is another institution, it's more than just nursing homes.

Providing the services and supports that a consumer identifies are needed.

Look at that language.

This is independent living at its very root.

Sometimes when you're trying to make it match into your waiver system in your state, sometimes that gets a little, I don't know how I can do both, but this is our law.

This is our mission to set out and do it in this way.

So we've got to keep that in mind.

And all of that language just really reinforces the independent living nature of this.

And then the second part of this is people who are at risk of entering institutions.

Again, I'm going to read it, listen for the independent living language.

Provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community.

A determination of who is at risk of entering an institution should include self-identification of the individual as part of an intake or goal setting process.

And we've always said, significant is in the law, that's who we serve, we serve people with significant disabilities as centers.

Sometimes people get stuck on that word significant.

Don't get stuck on it.

It is who we serve.

And that determination is a self-identification process, that's what we've always said.

Now we know though, that some of your funding sources require something more for identification of disability.

That's fine.

You have to meet those requirements.

You can advocate for ways to do them in the least intrusive way possible, but most of the time when you start talking to somebody about this, you're talking to them about their ability to identify for themselves that they have a disability and identify for themselves what they are going to need to live on their own in the community.

Now, sometimes when you get the referral, they're not ready yet, and you're going to have a lot of conversation about that.

So as we go through the different service models, you are going to see more complex ways to do some of these things, but listen to the simplicity of the law.

So the simplicity of the law is where you want to kind of anchor yourself, and then you figure out what you have to do to meet your different funding source requirements and what you need to do for it to work well in your community specifically.

I'm not going to get into that third one, because we're not going to treat that today.

But that's the transition for youth who are individuals with significant disabilities for transition.

Now, this is also in the regulations.

It says to be eligible to receive funds under this part, the center must comply with the standards back in section 725B and the assurances in section 25C of the Act with the indicators of minimum compliance and the requirements contained in the terms and conditions of the grant award.

A lot of the language in those two parts of the Act is different than it used to be.

And we're kind of still expecting the rest of it to come out, but the indicators are gone.

We used to do this training called the standards and indicators, and we came out and said these are the standards to be a center and here are the indicators and that's how they are going to review you to judge whether or not you are right.

Well, they're working on their review process, and it will probably come out in some other format for our review at some point in the future, but a lot of that language is gone, so when people are saying to me, give me chapter and verse on why we have to do this, and I go look for it and some of it isn't there.

So be aware and keep your eyes open for when the indicators come out, because they're going to have to kind of, and one of them is this self-identification of disability.

That's one of the things that they have said it in some subsequent letters on some parts of this.

But that self-identification of disability used to be in the indicators, now we don't have indicators, so we're waiting to get that back into the mix.

Kind of an interesting thing, I think it took all of us a little bit by surprise.

It wasn't until afterwards that we are going back looking and we are saying but the indicators were also supposed to be released, and they still haven't been.

So that gets a little, leaves us with less solid information on a couple things.

Your grants Program Performance Report is also going to contain a lot of information about your goals, including for this process.

Now, that's what we used to call a 704 report.

We still mostly call it the 704 report.

But that report is the annual report that we all provide, right?

And so we need to be thinking now about how you're going to provide information on these services, because you're supposed to be doing them now.

The law went into effect the day it was signed, so since 2014 we've been required to do these transition services, and then that means we have to, we're required to report on them, but the report hasn't changed yet.

They're kind of discussing some possible options for that, and putting off the date a little bit longer.

Right now, you have to do it within the current 704 report format.

Here are some places that you want to look at that.

In your achievements, you want to make sure your goals and your objectives and your measurable outcomes relate somehow to this new service of transition.

Right?

So your achievements, challenges, any of the issues that you came up with there, comparison to last year, your work plan for next year, all those things are places where you ought to be capturing this new core service of transition, and each component will have to be captured, as people give you details about how their systems work, you'll get a lot more of that information.

How are you going to in that report reflect those transition services?

Be thinking about that as you go along.

Make some notes about it.

If you have a brain storm about it, please put it on one of those green sticky notes so that we can all share that.

Or raise your hand when we're discussing it and tell us about it then.

But we need for you to participate with us in figuring out how we're going to do this, because the report isn't naturally set up yet.

So we have to kind of weave it into the current report system.

So are you keeping track of those components of transition.

Moving from an institution, preventing institutionalization and youth transition.

Because those are the things you have to report on.

So I won't spend a lot more time on this, but to drill down just a little bit, the facilitating of transition from nursing homes or other institutions to the home and community based residences with requisite supports and services.

What it says is this process may include providing services and supports that the consumer identified are needed in order to move from an institutional setting to a community based setting.

That may include systems advocacy requiring the person, for the person to move to their own home or the home of their choosing.

As you look at that, you just see, systems advocacy is going to emerge as a real significant part of what you're going to have to do here.

Because the system is what's allowing people to be institutionalized who really want to be in the community.

The system is an issue.

And we've got to figure out how to create something side by side that brings people out of that system.

So systems change is always going to be part of what you're doing here.

The institutional diversion, some of the language to look at here is the self-identification language.

And it shows up here and then there is also a letter that makes it clear that it also applies in some other situations with youth.

We've been calling this diversion.

Now they're kind of calling it diversion at ACL too.

Diversion is a great word for it.

It communicates, doesn't it?

People are almost into an institution, and we want to divert that.

So we have to have ways to know that they are at risk, to have them contact us.

It simplifies our communication I think to call it diversion, and that is so those are the people who are at risk.

A piece of that that I think is really important is you ought to be asking everybody you work with, are you at any risk of entering an institution in are you at any risk of losing your place?

Do you think there's any point at which what you're telling me about right now is going to put you in a risk situation because we want to prevent that, so let's talk about that as you come into our services.

Now people are going to give you a lot of their tools and information about how other centers are doing this identification piece, but don't forget the simplest, which is ask everybody you see.

We got a comment here, Tim.

AUDIENCE MEMBER: I actually agree with that.

I think the biggest trouble is too many times we ask a basic question like that.

The gut reaction from anybody is, no, I'm fine.

PAULA McELWEE: Yeah, that's right.

But they need to know that you're asking, and then tell them why.

Say because we really feel people ought to be in the community.

So if you ever are in a position of risk, please let us know, because that's one of our main things is to make sure you don't end up in a nursing home and you want to stay in your home, let us work with you on that, because we want to make sure people stay in the community.

That gets your philosophy right out there in front with every person you talk to, right.

So you want to make sure that you have a way to say to people, are you at risk?

And you may have to ask more than once.

But if you've asked the question, they're more likely to tell you as it deteriorates.

If you haven't asked the question, a lot of people hold things in or don't want to face the truth, and so you may never hear until you're really scrambling to try and keep them from that crisis.

AUDIENCE MEMBER: One of the things with that and being a CIL is that a lot of individuals that come into your center, they don't know what being at risk is.

So it is actually up to us sometimes to walk through that self-discovery of what makes you at risk.

Sometimes it's not merely asking you up front, are you at risk.

Because like you said, you're not going to get that if they don't understand t those factors that makes them at risk.

PAULA McELWEE: Absolutely.

I just also feel like we ought to be asking up front too.

Not as the only way would we seek out that information, but as a way of letting people know very early in the process that we don't want them to be in that risk.

But I love the materials that you all are going to present later.

I looked at them, and they're wonderful materials for getting to that question with people.

Cause you don't want a just yes, no answer.

So you will get more information as we go along there.