PAULA MCELWEE: We're going to talk about the law and what the final regulations say.

If you are the person who gets the ACL e-mail for your center, you had new information in your inbox this morning that you may or may not have seen.

We saw it about 6: 30 this morning, and we did layer some of that into what we're going to say.

But the Administration on Community Living came up with FAQ, as in Frequently Asked Questions around youth, specifically, and a cover letter from Bob Williams and a four-page question and answer was just released this morning.

We will layer it into what we're saying, but it was some clarification that we were specifically asking for.

Because some of the law could be interpreted in different ways and we asked for specification and some of that specification came through this morning.

It's new and fresh, and we're going to tell you what we think it said, but don't be afraid to say, that's not how I read it, because I really read it fast.

So what the laws say, what the regulations say is part of what we're going to cover.

What falls under the new core service and what doesn't.

So we have this new core service of transition and one element of that is youth transition.

What falls there is reported there and tracked there and what falls in other places under your other services.

We're going to talk a little bit about what the proposed Program Performance Report tells us about this core service.

Because they issued, ACL has issued a sample of what will replace the 704 report sometime, date not yet determined.

Maybe this next one you do.

But we know some things from what they wrote in that document about how they're seeing youth.

And strategies for tracking the service for reporting services.

So we're going to go through all of these different areas and the questions that are coming up related to them.

Oh, and I didn't change the slide.

There we go.

Just some background in case some of you are new to this.

Advocates throughout the country were active in seeking for this new core service to be added to what we do.

So I know sometimes people will say, well, you know, my center doesn't want to do that.

Well, centers as a whole, your peers as a whole advocated for this, went after it, and really wanted to see this happen.

Because we know that youth services are so essential.

So if you're in a situation where it's hard for you to apply this, now you are required to.

So I know the unfunded mandate is a question that we can't answer, but the fund raising people we will talk to tomorrow about some strategies for where you can find some funds, but it is something we wanted to see.

It's interesting that when WIOA, which is the Work force Innovation and Opportunities Act, when it was passed, it didn't only affect Title VII of the Rehab Act which is where independent living falls.

It also had changes in Title I of the Rehabilitation Act, which is where Vocational Rehabilitation falls.

So if you've seen some new activity in your state around youth for vocational rehabilitation, it may be flowing from their set of new regulations related to what they're doing with youth.

We're not going to go into that in this regulatory part, but as you hear about different peoples models and how they are funded, you will see that VR piece coming in.

Vocational rehabilitation piece coming in because of that.

Do remember also that the centers have been required to serve all ages and all disabilities from the very beginning.

Now the reality is for people under about 14, most of the time all we're doing is information and referral for their parents, trying to get them plugged into the right places.

They're very young and not yet really involved in any other disability-related activities, so often that's where it falls.

It has not been typical for centers to provide very many services for that very young age, but it is certainly possible.

It's always been required that if someone comes to you who is a preschooler, of course in that case it will always be their parent that comes to you, that we do at least help them with information and referral.

And the other core services may or may not apply and I think most of the time we find they don't.

But from preschool on up, it's always been a part of our requirement.

Sometimes when I say these things, I look out at some of you and I am getting a wide-eyed look in response.

And I think that means you didn't know that it has always been part of a requirement.

And all of us struggle a little bit with that because it has never been enforced.

Nobody's ever looked at it when they've come out to do an onsite review.

The fact that all ages and all disabilities were both required kind of makes us a little, you know, really?

Remember, requires that you keep your doors open to them, not that you have to provide all core services to them, but that you keep your doors open to them.

And information and referral at a minimum is to be provided.

Moving on to slide nine.

This is the first place where you're going to hear a little bit about what we thought this morning.

The law references youth transition as one of a core service call transition.

It actually has several elements.

We're going to do other training on some of those other elements later, but the youth transition is the specific one we're going to talk about today.

The law indicates this service is for post-secondary youth.

We're going to spend a little time talking about what is post-secondary.

Who had or were eligible for an IEP when in school.

So that is a specific way we want to look at it.

We're going to look at those two elements first: What is post-secondary, and when is a person eligible for an IEP?

Because I think that is where a lot of our questions have been.

Exactly how do we count this or what do we do with this.

Let's look at that post-secondary piece first.

The law indicates that these services are post-secondary, which means after ending high school, and extend through age 24, up to their 25th birthday, through age 24.

So up to their 25th birthday.

So that's the age group that we're serving.

They cannot be in school any longer, they've ended school, and they haven't turned 25 yet.

So they're post-secondary if they're out of school.

One of the very interesting pieces of clarification this morning was if a person left school and is now enrolled in a GED course, they are still post-secondary.

That was kind of mind-blowing for me.

I was thinking that's just another adjunct to the school, but they're saying no.

They are saying those are post-secondary youth.

I'll give you a second to absorb that one.

And the services that you are going to be providing, this is the definition of them: services that facilitate the transition, this is slide 10, facilitate the transition of youth who are individuals with significant disabilities and who are eligible for individualized education programs under Section 614d of the Individuals with Disabilities Education Act, and who have completed their secondary education or otherwise left school to post-secondary life.

On the next page you have the definition of completed their secondary education means with respect to these services, that would facilitate the transition of youth who are individuals with significant disabilities.

That definition is also in your packet if you need it.

And that that eligible youth has received a diploma, has received a certificate of completion from high school or equivalent document marking the completion of participation in high school, or has exceeded the age of eligibility for services under IDEA.

Now one of the reasons that we asked some of the questions that we did was this doesn't allow for somebody who leaves school because they're dropping out or because their health conditions did not allow them to continue during that period or whatever.

They have clarified that those folks would also be post-secondary.

I think Sierra has for us some ways to look at this or questions that we might look at to make sure this is clear for us.

Let's hear from Sierra.

SIERRA ROYSTER: Is this on?

I put around the room some easel paper.

On each one there is one of the core services.

You will notice that there is seven.

I took what Paula had just said, the last core service that just got added is "under transition." It's a three-pronged piece to that.

So I broke those out.

I have a youth transition.

I have a nursing home and other institutions to community-based living.

And the back is diversions from institutions.

That's why we have seven.

It's okay.

It's all under transition from core service.

PAULA MCELWEE: We started calling this the fifth core service, and we were corrected that we can stop counting them now.

We don't have to say there are four core services.

We just say there are core services.

You can count them as five or seven or whatever you want.

SIERRA ROYSTER: So what I want to do, this is a hard to understand.

You can read it all day, but until somebody walks into your center and says I would like service and then you serve them.

And then you go oh wait, how do I report that, that's when it gets tricky.

I want to give examples, and I have asked for volunteers at each of our tables that are closest to the paper on the wall.

We're going to do this as a group.

If you think you know what service this is, we're in a perfect world with plenty of funding, and we provide all the services to everybody, just to set the stage.

An 8-year-old who needs help advocating at an IEP meeting, what service does that fall in?

PAULA MCELWEE: I don't know what you had in mind?

SIERRA ROYSTER: That's fine.

AUDIENCE MEMBER: Peer support and mentoring?

SIERRA ROYSTER: Peer support and mentoring, what else?

AUDIENCE MEMBER: Independent living skills.

SIERRA ROYSTER: Independent living skills, depends on what you're doing.

If you're going to teach them to talk at the IEP meeting.

AUDIENCE MEMBER: Individual and systems advocacy.

SIERRA ROYSTER: If you were going there to advocate for an IEP with the parent, then that would be the individual and systems advocacy.

And there are eight, and that doesn't fall under the transition service.

That was the tricky part of that.

PAULA MCELWEE: So it falls under the regular individual and advocacy services that you already provide to any age and it does not fall under transition when you're reporting it.

SIERRA ROYSTER: Okay.

Nice little warm-up.

A 14-year-old wants to learn how to use the bus.

Where does that fall?

PAULA MCELWEE: Raise your hand please, and we'll get you a mic.

AUDIENCE MEMBER: That would depend on what state they're in.

SIERRA ROYSTER: Remember, I set the stage.

We're in a perfect world.

We have public transportation.

AUDIENCE MEMBER: It still depends on what state they are in.

Minnesota is 14 for transition.

SIERRA ROYSTER: But what service does that fall under?

AUDIENCE MEMBER: Depends, again.

SIERRA ROYSTER: If you're in Minnesota.

AUDIENCE MEMBER: It also depends on why they're there and why they want to learn to use the bus.

Is it to go to work?

Is it to, what is it for?

SIERRA ROYSTER: Do you have a question or comment?

AUDIENCE MEMBER: More of a comment.

So, they're trying to learn how to use a bus?

It's a learning skill, it's to become independent.

Independently of why the purpose of the the bus.

SIERRA ROYSTER: Okay, so it could be an independent living skill.

But what's the one question that you want to ask yourself though?

Paula just went over it.

The age we have, they're 14.

AUDIENCE MEMBER: If they're still in school.

SIERRA ROYSTER: Are they still in secondary education?

Because if you're talking about if they're still in high school, maybe a freshman in high school, that may, is that going to fall under transition youth services?

Is it?

No.

Because they're still in secondary education.

See how I told you I was going to trick you?

I gave you a warm-up.

So they are still in high school, which is the secondary education.

So that's not going to fall under the transition services.

But, can we still serve them?

As an independent living skills training, if I can get it out.

Does that make sense?

Did I lose everybody?

Okay.

So looking at the question as it is, the age, you also have to look at where they're at for education at that point.

Okay.

Okay.

A 14-year-old wants to learn to use the bus.

And they have left school at 14.

I was just testing you.

They're doing a GED program.

AUDIENCE MEMBER: I got it this time! Transition.

SIERRA ROYSTER: Transition.

Okay.

So if they leave school early for a medical condition or because they just decided to leave, they now fall out of just secondary education.

They are considered in transition services.

AUDIENCE MEMBER: Can I ask you for clarification?

Okay, so if they were 14 and not in a GED program and they didn't finish school, is that still post-secondary?

SIERRA ROYSTER: They're not in secondary education anymore.

You hold on.

Don't jump ahead.

You're going to ruin my example.

That's fine.

That's a good example because we actually have that.

If I can find it, I will do that one next.

AUDIENCE MEMBER: If the state you're in does not allow a student until they're age 15 to go into a GED program, so this 14-year-old you're talking about falls in the gap, then we keep looking at them as secondary until they become enrolled in GED?

SIERRA ROYSTER: Have they left secondary school?

Then yes.

Once they're out of secondary education, they fall into the transition services up until their 25th birthday.

AUDIENCE MEMBER: Do we not have to take into consideration whether they were under an IEP or eligible for an IEP?

PAULA MCELWEE: That's the next section of regs that we're going to cover.

This is just are they post-secondary.

We want to clarify that so everybody is clear on who is post-secondary.

And the GED question comes up only because it's school-related.

And in the beginning we all thought, oh, it's school related well then if it is school related it must still be that they're in school, and they have clarified that no, they left school in order to be eligible for a GED program.

So it does not count as school.

They can still be post-secondary even if they are in the GED program.

SIERRA ROYSTER: One more question, and then you go ahead.

AUDIENCE MEMBER: Okay.

So, with transition, the word itself implies the transition over the process.

So it's not just picking up after they've been dumped by or been to one program.

So I'd like for you to address a little bit about what we can do, because we can serve them under the all ages category.

So we can serve them maybe not categorized as transitioned but it is leading up to the transition ahead of time.

PAULA MCELWEE: You may want to take a look at what you call your programs.

I think some of the confusion about whether or not it's a transition program is coming directly from the fact that you've been calling it that.

And they've been doing that with all 14-year-old programs in high schools where the students themselves are transitioning and we've been calling it transition.

And so that has created some confusion.

We don't care what you call your program as long as you're clear that unless they are out of school, you don't count them on your report as transition.

They have to be post- secondary to count them on your report as transition.

I hope that makes it a little bit clearer.

This designation is for the purpose of showing that you are indeed providing some transition service.

Hopefully that kind of makes sense.

Let's move on.

Jot your questions down if we haven't quite gotten to them, and I think we'll get to most of them here before we're done.

Okay.

So the core services definition, the core services that have to be in place for youth transition include services, this is right out of the regs, this is a continuation of that same regulation.

Services that facilitate the transition of youth who are individuals with significant disabilities, we'll come back to that, who were eligible for individualized education programs, that's the next topic, under Section 614d of the Individuals with Disabilities Education Act, and who have completed their secondary education or otherwise left school to post-secondary life.

If they have reached age 18 and are still receiving services in accordance with their IEP, they have not completed their secondary education.

So usually in the schools, it's only to age 22.

Some states have a little bit different definition.

But if they are still in school, they are not post-secondary.

You still count them in your regular counting of services provided to people of all ages, but not as a transition service.

Okay.

Let's talk about the disability part of this.

So a youth with a significant disability means an individual with a significant disability who is not younger than 14 and is not older than 24.

Remember this doesn't have to do with who you can serve but how you report on your report, on your PPR, Program Performance Report, that's going to replace the 704 report.

So on the PPR, you have to say what age were they and if they are not younger than 14 and not older than 24, they count in the age group of youth.

That gives you an overlap when you're counting people in the age group of youth, some will be transition, and some will not.

So I'm not going to go into that in any more detail.

I think we covered that one.

Regardless of disability.

The significant disability language is the language that is in the law now for all the services you provide.

Not all centers use that language and, it's self-disclosed disability.

But you are expected to determine if people are eligible for independent living services.

That's always been the case, almost always.

It's been the case since the '80s.

So it's something that you would be expected to do.

You would be expected to do what?

Ask them.

You're not expected to do a test.

You are not expected to ask for medical report.

You are not expected to do anything to determine eligibility except to ask the individual.

Or in the case of a minor, you may ask the person who is responsible for that individual.

So centers can serve all ages.

Always significant disability.

And if you have other income, you can serve other people too, your center can.

But you have to make sure that your dollars that come from either Part B or Part C of the Rehabilitation Act, Title VII of the Rehabilitation Act.

Those Part C and Part D monies have to be used for people who have a significant disability.

If the disability is not significant, I'll give you a definition in a second, or if the person does not have a disability, they can still participate in some of the activities that you have.

How would they do that?

Because you have other money to show that you can include them.

Sometimes including those folks doesn't cost you anything extra.

You know you have a big group and it does not cost you anything extra.

So that's great.

One or the other has to be the case.

If you include more than people with a significant disability.

a significant disability.

That's true for all the services you provide by the way.

So does that kind of make sense.

If you fund events for youth and you get sponsors and some of the other things and ideas you will get tomorrow, all youth can attend, I know a lot of us would like to see a lot of integrated activities that we might be a big part of.

But as you work on that you just have to remember that you can't pay for any of the other people with your Title VII money.

Okay, lets look into this one.

AUDIENCE MEMBER: I just wanted, hello?

I just wanted to double check on a previous question.

So folks that are in the transition, like post-secondary, because they're still receiving services through the school, they're not counted in the youth program?

Those if you are in Colorado, 18 to 21, they're not counted in the youth program?

PAULA MCELWEE: They're counted under youth because that's their age and demographic information, but they're not counted under transition.

They're counted under the other core services.

Who else?

Did you want to say something?

AUDIENCE MEMBER: So for youth with a significant disability, we've talked about the definition being youth who is eligible for an IEP, what if a youth was, for those youth who had a 504 plan while in school but did not have an IEP?

PAULA MCELWEE: You're jumping a head a little bit.

We will get to that next.

We're still talking about who is eligible and we're talking about significant disability, that piece of the eligibility.

So are we clear on significant disability, cause I know you're all dying to talk about the IEP.

It is a big issue.

AUDIENCE MEMBER: We would like more clarification on what significant is.

PAULA MCELWEE: The definition just went up on the screen.

This is out of the law.

What I do when I ask somebody do you have a significant disability.

I say here is the definition but you decide.

You tell us, we're not going to have somebody else assess you.

You tell us: Does your disability cause significant limitations for you in anything in your life?

So it talks about your ability to function independently in the family, in the community, to attain employment, does your disability affect those things?

And a lot of the times the answer is yes, because of community prejudice, not because of individual ability.

But you let the person answer however they want to, based on what they know about their world today.

So it's self-disclosed.

And that's also going to be true about the next part we will talk about, self-disclosed.

This is something that has been very important to independent living for a long time.

Early in the preparation of these regulations and from time to time as we talk about it and as we continue to evolve a little, someone will come forward and say, but that disability isn't significant enough to count.

Well that is not your decision to make.

It's the individual who is saying, yes I have a disability who says whether or not their disability is significant enough to count.

No one else gets to make that decision, only the person themselves.

AUDIENCE MEMBER: So if you had a disability or have a disability and you got the services you needed and it no longer really troubles you, you would theoretically not have a significant disability anymore because you have the coping mechanisms to get over it?

PAULA MCELWEE: That's a really interesting way to look at it.

When I quizzed on that with the powers that be in our funding structure, what they have said is that even though it's not written there, we assume this would be without any program services or adaptive options.

So if there was not accessible transportation, if you didn't own your wheelchair, if you didn't have the advocacy skills, would you still count it?

But I know some of you really want to see a precise definition here.

You will never get one.

There will not be a precise definition of significant disability, because that is who we are.

We are a community of people who declare, "I have a significant disability."

AUDIENCE MEMBER: I was curious because the state and government label it a little differently according to SSI benefits, and that's part of the battle.

You know, we can't determine what they put down if that's a significant disability.

That was a culture shock to me.

I thought, you know, if I receive benefits from the state, I'm obviously disabled.

So somebody who just says they're disabled can get Section 8 housing, and all of this other stuff.

PAULA MCELWEE: Oh no, I'm not saying this affects any other federal law.

It only affects independent living.

So as we look around at our community, we are a community of people with significant disabilities.

That's who we are.

As that community, we are coming to the table and doing advocacy and participating in all of these core services.

Some of that advocacy will be helping somebody prove their disability in another realm like housing or some other place.

But we can't, their definition is their definition.

AUDIENCE MEMBER: Can I say briefly, because I happen to be a working centers counselor.

It's one of the things I run up against, constantly having to say the ADA's definition and independent living's definition of disability, is not Social Security's definition.

They are completely different.

I will always be a person with a disability.

I do not meet Social Security's definition to qualify for disability benefits.

They're not the same thing, and I know they are extremely confusing for us and also for the consumers that we serve.

AUDIENCE MEMBER: Paula, what makes me nervous is the distinction that has been put into the regs between staff with a disability and board members with a disability focusing on the significant disability part for the board members, wherein we are, and a lot of times there are consumers who we have been able to add to their success in life to remove some of the barriers from their daily functioning, which would leave them as a person with a disability, but may not leave them under this definition of significance.

PAULA MCELWEE: They will self-declare whether they feel their disability is significant or not.

So it can worry you as much as it needs to, but the law says board members have to have 51 percent of people with significant disabilities.

That is what the law says.

Some of you have been ignoring that little word, it was not slipped in, it has been there from the beginning.

Because we wanted to have the people we serve represented on our board.

And we serve people with significant disabilities and 51 percent of our boards are people with significant disabilities.

We do not make the same distinction in staff primarily because we can't ask staff that question when we're hiring them.

We may or may not be able to see that they have a disability.

We may or may not be able to.

They may or may not be wise enough to tell us about a disability during the interview process, but there are other laws that get in our way.

So the word was removed in relation to staff because of legal issues.

But it has always been there in relation to who we serve and in relation to the majority on the board.

AUDIENCE MEMBER: So I have more of a question on the other end of significant disability.

Where do we kind of draw that line?

Because typically I know that we can't duplicate services, so, in Washington state, we don't typically serve people that are, that already have a case management with DDD services.

So it makes it difficult to figure out where that line is.

PAULA MCELWEE: That's really fascinating because we consider our services to be distinct from DD services, and there is duplication in most states.

We don't draw that line.

Now your center may choose that people may be better served with information and referral because you can't provide what they need for some reason.

Then you certainly can collaborate with other entities in your community to make that happen.

But there has never been a distinction in the federal law that says you can't serve someone who is served by some other entity.

In fact we encourage collaboration between entities in the community.

Aren't we having fun?

I think we've beat this one up, so I'm going to go on.

You know, sometimes I find that as we're struggling with the regulation, we're struggling in part because we haven't seen how we can implement it in our environment at home.

But the regulation is still there.

That doesn't change the fact that you have to figure it out.

It would be easier for some of us if we didn't have to figure it out, but we have to figure it out.

Okay.

So let's look at a couple of other services.

So advocacy is a service that we provide as a core service, right?

Advocacy is another service that you may very well provide besides information and referral to all ages.

Preschool, grade school, junior high or whatever they call it now.

Middle school, high school, all of those ages may have advocacy, and we had an example of that just a minute ago in negotiations, remediation, or informal administrative procedures before government agencies and legal proceedings in a court of law.

So you might be involved in representing an individual in all kinds of settings.

Now you may have some policies around when is a lawyer needed.

Some of your centers hire lawyers for that very reason, for good advocacy.

But as you look at that, advocacy is going with an individual and helping them or helping them with self-advocacy or helping them with systems advocacy.

So there's three components.

You might assist a person with advocacy.

You might teach them to be self-advocates.

You might get a group of people together who have the same concern and as a group you do advocacy related to what's happening in the community at large.

With that service, you can provide it to whom?

To everybody.

Youth or not, transition or not, advocacy is a service that we provide.

So it shows up under advocacy and transition.

It can be a transition service.

How about peer stuff?

We do a lot of peer relationships, usually, with youth right?

That's one of the best ways to grow your program is to have good peer relationships.

So that's another core service that has always been provided.

Sierra has an example of that.

SIERRA ROYSTER: Now that we've confused you and you've memorized the ages and requirements.

Youth group is a gathering that has food and games.

The youth help plan it, they budgeted for it, and put on the whole entire youth group.

Where does it fall?

Peer support.

PAULA MCELWEE: I'm hearing peer support.

SIERRA ROYSTER: Yell it out.

AUDIENCE MEMBER: Where did they get the funds to budget it from?

SIERRA ROYSTER: That is tomorrow.

PAULA MCELWEE: It is pertinent.

If it is in Title VII, then it -- it's not really pertinent is it.

SIERRA ROYSTER: They raised the money themselves.

It is not Part C or B.

AUDIENCE MEMBER: So it depends on if they are transitioned or not?

SIERRA ROYSTER: How old are they?

If you have a mixed group and some people are 18, 19, 20, where do they fall?

AUDIENCE MEMBER: Transition, typically.

PAULA MCELWEE: It depends.

AUDIENCE MEMBER: They might be doing GED.

You don't know.

SIERRA ROYSTER: So you need to know their age and educational status, where they are at.

PAULA MCELWEE: Are they post-secondary?

SIERRA ROYSTER: If they're 25 in that youth group?

AUDIENCE MEMBER: If it's a mix of kids, would it be that you enter them, so we're going to go into our database and are we going to enter them individually?

SIERRA ROYSTER: Yes.

Yeah.

PAULA MCELWEE: So some will be transition and some will not.

SIERRA ROYSTER: If they're over 25, where do they fall?

Peer support, I hear?

AUDIENCE MEMBER: Depending on when their birthday is.

SIERRA ROYSTER: Depends on when their birthday is.

But once they turn 25, on their birthday, they are no longer eligible for the youth transition piece.

So think about the service, though.

So the budgeting.

Is that a skill?

PAULA MCELWEE: IL skill.

SIERRA ROYSTER: IL skill.

Putting together an event.

Planning, team work, that type of thing.

Those are skills.

I have the same question for you.

A group of young people is putting together a group to play games and have fun.

Recreation.

What is that as a service?

What's the first question we've got to ask?

AUDIENCE MEMBER: Okay.

So are we assuming that all of the participants in this peer group activity have complete CSRs?

SIERRA ROYSTER: Yes.

I like how thorough you all are.

So they are mixed ages.

What are they receiving?

They didn't budget for this.

They came, hung out, they got to see other people their same age.

AUDIENCE MEMBER: Peer support.

AUDIENCE MEMBER: What is CSR?

PAULA MCELWEE: Consumer Service Record.

And you are required to have a Consumer Service Record we can argue complete later.

You are required to have a Consumer Service Record for anyone receiving services except for information and referral.

That is currently the requirement.

SIERRA ROYSTER: So if they have a Consumer Service Record, they're there to have fun, they're learning from peers in the group, where does that fall?

Some of you said it right around here.

Peer support and mentoring.

So it depends on what your group is.

But also looking at the ages and looking at where they're at in education.

Are they still in secondary or are they out?

Are they over 25 or under?

PAULA MCELWEE: They may all have the same goal if you established a goal for your group, but they won't necessarily all have the same goal in that Consumer Service Record.

They have goals that have been set.

Even if they waived an independent living plan, you have written down goals.

And they could all have different goals that are being met during this time.

So somebody might have a goal for the money management piece.

Somebody might have a goal for being willing to speak up in a situation and other life skills.

Different things might be different goals of different people that are there.

That's okay.

Not everybody in the place has to have the same goal.

I do sometimes see where people agree that the group agrees what goal they're working on together and they each put it their CSR.

That seems equally complex.

So I don't know which way you do it, but it can happen either way.

One of the things that we have here is one slide, slide 22, just remember those of you from SILCs or serve on your SILC, you must address youth in your SPIL, Statewide Plan for Independent Living.

The SILC is the Statewide Council for Independent Living and that creates a state plan.

So the state plan for independent living should include youth.

Sometimes as an underserved population, there's a section of the plan that looks at who is underserved, and some of you are here because that is an underserved population in your state.

The centers are just now getting to that conversation, and so you're really working on it as an outreach to underserved people.

Other statewide efforts or events can also be included in the SPIL.

Who has other ideas?

Anybody have things that you include in your SPIL that you would like to share?

AUDIENCE MEMBER: Some of the things that West Virginia included in their SPIL to get the youth involved is to have a youth council and then have a youth on the SILC council like on the board.

We were trying to get youth on all parts of the board.

PAULA MCELWEE: Which is also leadership development, right?

So as you look at it, it is something that can help you develop the leadership that youth have so that they can also be the board members for centers or whatever other leadership roles might come.

So that's really good.

AUDIENCE MEMBER: So my question is, what if, I come from a CIL in Washington state, and right now I'm coordinating with our local university with students with disabilities at the university with youth in high school.

But the only catch is, is that some of these guys are over 25.

But you're still going to consider that peer support, regardless; correct?

PAULA MCELWEE: Yeah, but you don't count them as transition.

You do count them in peer support and not transition.

Most youth, they become mentors, as they age out, they become mentors for the other youth.

So there's that wonderful development of leadership that happens.

AUDIENCE MEMBER: The only thing I want to add is also from a centers perspective, we added a youth to our board as well to start getting the youth perspective incorporated into what we were planning.

PAULA MCELWEE: Some states you have to look at the age of that youth, whether or not they're allowed to serve on the board.

But remember youth goes up to 25, so of course they're allowed there.

AUDIENCE MEMBER: I'm rethinking our SPIL, and I was not the SILC director when the SPIL was written.

That is kind of how I got into this role.

We were pushed by our DSE on the definition of what was youth to put youth transition in as.

There was a lot of argument going back and forth between some of the centers and individuals from the community talking about, you know, programs and services.

And we got pushed really hard by our DSE that no, it can only be the official definition.

And I'm thinking now that maybe our SPIL needs to be amended to include youth programs and services including transition.

And just to be a little bit more clear on it.

PAULA MCELWEE: Yeah, I think that's good language to take a look at.

Because when they put out the PPR and they included 14 and up, they had students and school as youth in the demographic information, that was a very clear indication that services can be provided in addition to transition for youth, and it can be the entire, you know, menu of core services plus other allowable services for centers.

So it is not, transition is not all of youth.

Youth includes transition, but transition is only one component of what youth can receive.

AUDIENCE MEMBER: So what about university students?

21-year-old post-secondary.

PAULA MCELWEE: They're post-secondary.

They're not 25 yet.

They might be.

AUDIENCE MEMBER: Had an IEP in high school.

PAULA MCELWEE: Which we are going to come to in a minute.

AUDIENCE MEMBER: But that would be under the youth transition?

PAULA MCELWEE: Yeah.

So you count them as a transition person, but they may also have goals under advocacy, peer support, independent living skills training, right?

So we have all of these things.

AUDIENCE MEMBER: I don't really have a question, more so, we have a program called Project Search.

It's a national program, but it's not everywhere.

We're probably the farthest west in Minnesota that it's offered.

Otherwise, Chicago is the next closest.

We have not been counting students that are participating in Project Search as transition because they can't receive their high school diploma until afterwards.

Just want to make sure that.

That's what we've been going with because they technically haven't graduated high school, it's like a super senior year of high school.

PAULA MCELWEE: We have new FAQs and what they say is if they're doing a program to get their diploma but they have left school, they still count as post-secondary.

That's new information, I mean very fresh off the press information, but you could rethink that based on that information.

You know, there isn't a, if you categorize people as receiving services and you don't categorize them under transition, there's not, you know, as long as you're serving people with transition services and you misqualify somebody as to are they in or out, post-secondary or aren't they?

What's the damage?

Nothing.

This is just how you report them.

It isn't whether or not you serve them.

AUDIENCE MEMBER: Paula, can you clarify just a bit on our traditional transition services?

If they have not received that diploma and they are involved in transition, this new information is kind of confusing.

Would they still qualify for that youth transition if they are receiving transition services?

PAULA MCELWEE: So there are other things called transition besides this core service, and that does create a lot of confusion, because when you sit down, you think I've got a grant with Department of Rehabilitation to provide transition services from age 14.

I go into the schools and I do classes for independent skills training, and I do all this.

Can I count them under transition?

The answer is that student can only be counted if they're post-secondary under the definition that IL has put in place.

But you can still count them for the definition that Department of Rehabilitation has for your transition grant.

So you're juggling definitions a little bit like with the whole eligibility piece.

It's going to be different for each funding source, very possibly.

And you may or may not choose to change what you call things at your center as long as the people reporting understand when do they call it transition on your PPR.

It isn't whether or not people are served.

It is where you count them.

Is this coming along okay?

Are you getting it?

It's been very confusing.

We know that.

AUDIENCE MEMBER: I probably have a very redundant question, but I have to ask it.

Many of our students go through the graduation ceremony, don't receive the diploma, go back and get transition services.

Where are they in the process?

PAULA MCELWEE: Are they post-secondary?

AUDIENCE MEMBER: That's a great question.

PAULA MCELWEE: That's how you make the decision.

If the school considers them post-secondary, you would say, okay, they're in transition services because that's what you have to be is post-secondary and in that age group.

If the school says, we still count them as current students, and I think they probably will in that case, then they would not be counted under transition.

SIERRA ROYSTER: So I wanted to address somebody asked a 504 question.

So example, we're going to put it up on the chart.

Student in post-secondary wanted guidance on moving out on their own who had a 504 in school.

Good job.

I didn't put that in there on purpose.

Let's say they're under 25.

Transition.

PAULA MCELWEE: That's the question, though, isn't it?

The student had a 504, not an IEP.

And we all came out and said, what is the deal there?

We have some students who don't have either but still have a disability.

And we have students who have a 504 plan but not an IEP.

And here's the new guidance that came out this morning, and that is that they defined further what it means when someone is eligible for an IEP.

I've got to find that.

I guess I passed it.

So I'll just tell you.

I need to find it in there.

But eligible for an IEP, they're saying now, that is also self-disclosed.

So whether or not they are eligible for an IEP is self-disclosed.

If you have somebody who is post-secondary who said I didn't have an IEP because, what was one of the examples, I was home schooled.

And we also had asked the question around charter schools and private schools.

I don't have an IEP.

Am I qualified for this program?

The answer is, you don't have to have an IEP.

You have to have been eligible to have one.

And you tell me.

That's the approach.

SIERRA ROYSTER: So the new FAQ says that they self-disclose if they're in a home school, which I know was somebody's question back there.

AUDIENCE MEMBER: What if they got the disability after high school?

And they didn't have the IEP?

PAULA MCELWEE: That's another good example, if it's an acquired disability that occurred post-secondary and they are still under that age of 25, then certainly you would still serve them, or count them here.

Again, let me say, it's not whether or not you serve them, it's where you count them.

You're going to provide the same independent living services to everybody and every age all across the spectrum of disability.

AUDIENCE MEMBER: Hi, so if somebody's 24 and they enter your transition program, and they age, like we will.

Do they get to stay in it until you are done with their transition service?

PAULA MCELWEE: That's up to your program and how you define it, but you can't count them anymore once they turn 25, but you can serve them anyway.

AUDIENCE MEMBER: With the Title I, with the DVR, and with the, I understand the IL side of it, but the, my question is with DVR, with Title I, with a lot of our funding, they're getting creative on how they're getting us to do some of their work and rightly so.

But they have, I'm assuming they have different requirements or qualifications of what, who qualifies for transition?

PAULA MCELWEE: Yeah, I don't have time to study all the regulations, and I don't know the answer to that.

But there are people here who have those grants, and those people who have those grants know what the requirements are and know what they're required to do related to that.

But the transition may have a different eligibility and different definition.

Everything may be different based on your funding source, Title I, from VR, and that's okay.

And you will hear more about this tomorrow.

You've got people who are doing exactly that, going into schools and providing those youth services even though they're not post-secondary yet.

And those youth services are part of what we're going to talk about.

It just doesn't fit the definition of transition, so you can't report it on your PPR as a transition service, but you can still serve everybody.

I know that that's confusing.

Some of you came, some of the resistance, let me put it this way, some of the resistance to this is related to the fact that some centers didn't serve youth before.

You know, do we have enough money?

Are we spread too thin?

All of those questions about economy come into play there.

That's part of why we're spending a good part of the day on how you can raise additional money.

But the reality is we were always supposed to serve youth, and some weren't.

So now we have to prove that we are serving youth, and this is how you are defining it in your report.

Okay?

AUDIENCE MEMBER: I was wondering about like maybe a cross-disability activity where there was maybe a little bit of CIL in with a church group, and then possibly the church group, we didn't know, they didn't know that there was, they knew that the CIL was invited with the transition part piece, and then once the youth group got involved and there turned out to be youth that had disabilities.

Once they found out that it was included with the individuals that didn't have disabilities.

So I was wondering what about that?

PAULA MCELWEE: You can certainly do integrated activities.

You can't pay for the non-disabled participants using your Title VII money, but you can certainly collaborate with other entities and you can pay for the portion or people that you would serve that are eligible for services and share that cost with the school district that might integrate the activity with other nondisabled peers as a part of that.

That is certainly allowable.

We have a couple other questions pending.

AUDIENCE MEMBER: Clarifying question.

Paula, you keep saying you can or cannot count under transition.

Would you, so we count some services under transition.

I want to understand, do we count also services under youth?

Is that another category?

So we can count either transition or youth?

PAULA MCELWEE: Youth is not another category, it's a demographic.

AUDIENCE MEMBER: Perfect, that's what I thought.

So the question that Sierra had, I believe the question was that the individual is transitioning from school to community.

If it is a transition service, but the individual is over 25, can't we still count it as a transition?

PAULA MCELWEE: No.

They can't count it as a transition.

They have to change that next year to counting that person instead as regular independent living services.

AUDIENCE MEMBER: What about the transition that the nursing home diversions?

Is that a transition?

PAULA MCELWEE: Good, good, good.

That is a transition, that is not age-related.

We have a question related to that.

AUDIENCE MEMBER: I don't have a question, but I'm trying to wrap my head around the reporting part of it.

And it almost seems to me that an IL center internally would have to take, first of all, focus on the demographics of the consumer, and many of the IL centers have multiple programs they provide.

So I'm wondering if their internal system would take and track the programs that the consumer enters into with a start and end date and within those programs, the different services that are being provided under that program.

If that would enable to correct the tracking of the numbers when we do our PPRs?

PAULA MCELWEE: Right.

So you have the number of software programs, most of your centers have one of the software programs that collect this information, right?

So you collect the information about the person, and they have goals and you have to tell where the goals fall in the services and so forth.

What is the purpose of all of that?

Think about it for a minute.

The purpose of all that is not to determine eligibility.

Although you had to do that up front.

The main purpose of that is to assist the person in achieving their own goals.

Does it matter what you call them when you want to help the person achieve their own goals?

It matters only in proving that you are indeed a real center for independent living because you are providing all of the required services.

The reason for reporting this is to prove that you're doing it.

It doesn't have anything to do with meeting the individual need of the person so much as making sure that you have reported it in a way that is your documentation that you provide the service.

It can be very flexible related to how you do it and what that person's relationship to your center is and for how long.

What you call them, all of those things.

That can be extremely flexible.

AUDIENCE MEMBER: So that's where my resistance comes in.

Typically I work with youth that are still high school students.

And then according to this, then they become youth transition students once they're out of high school, but they're still receiving the same services and in the same programs.

So do we just count them as youth to begin with and then youth transition after that?

PAULA MCELWEE: That's what I'd suggest.

You have to prove you're providing this new service of transition.

So the only way you're going to be able to prove that is if you actually record that as they move in age or status, school status as they move through.

AUDIENCE MEMBER: But are we, in fact, providing, I know for our center anyway, we are providing youth transition services usually along with the school, because they're transitioning out of high school into independent living.

So when you're documenting what you're doing with the youth regardless of whether they are still in school or not, isn't that providing proof that you're.

PAULA MCELWEE: No, because some of the people that you are providing services to, do not fit the transition definition.

They are not post-secondary.

You can only count them as youth if they are post-secondary.

As long as they're in school, you have to report them on the regular place.

As soon as they're post-secondary, then you count them as youth as long as they're doing transition until they're 25.

The purpose of this, remember, is not for that individuals plan.

This is your recordkeeping and your documentation to prove that your center is doing the service.

We need to kind of keep the, you know, you still need to do what the person needs, and you have to figure out how you're going to define that or what that's going to look like in your center.

You probably will have program descriptions and you probably will think around some other things that will help you to manage the reporting piece.

But I can't say it enough times, and maybe I'm overworking it, but it doesn't change how you provide services if you have been providing youth services.

What it changes is if you have not been providing them, now you must.

But if you were already providing them, you're ahead of the game and you just have to figure out how to classify people on your database.

Which all those companies are working on.

AUDIENCE MEMBER: Why didn't they keep it simple why say anybody under 24 is youth and we're good with that?

PAULA MCELWEE: Yeah, I know there are many days when I read a regulation and think, why couldn't they have made it simple.

But these are the regulations that you'll be held accountable for.

And an interesting thing, once they start doing site visits again, an interesting this is ACL has not done site visits of centers for two and a half years.

When they get that up and running, they will be doing as many as they can get done.

The number in the law probably exceeds their capacity.

You can, a lot of you, expect to see some site visits kicking in just as soon as they get that system up and running.

So you do want to make sure that you've thought about whether or not you're meeting regulations, because that's what the site visit does is determine whether or not you're meeting regulations.

AUDIENCE MEMBER: So if I'm working with someone who's 23 and they're out of school, then they can be counted as transitional, but if we're working together with voc rehab and they're contracting with us, how do we count that in our data system so that we are, or can we?

PAULA MCELWEE: That's just your funding source and you may have specific reporting you have to do for Voc Rehab related to that individual's transition plan right?

Transition plan or whatever they call it.

AUDIENCE MEMBER: Right.

PAULA MCELWEE: You do your own reporting to ACL, Independent Living Administration related to your Title VII funding program.

AUDIENCE MEMBER: Okay.

AUDIENCE MEMBER: I just wanted to ask, is there going to be a certain requirement of the amount of youth to be transitioned placed on our center?

PAULA MCELWEE: At this point you will set your own goals for how many people you think you can transition.

Centers are so different from one community to the next in size and scope, and that isn't something at this point that is really being regulated.

What is happening is that you present to ACL your own goals every time you do your renewals and your year-end report, you say what your goals are, and then they will hold you accountable to those.

Nobody else is setting those.

You're setting those yourself and then holding yourself accountable.

AUDIENCE MEMBER: My question is piggybacking off of the last question.

Transition is most of the service that I provide is before they actually become youth transition.

And then what I foresee is that as soon as they graduate, they're going to move on to the goals that we've been working towards and they'll only be youth transition with me for, because I live in a rural community, they're going to move away and they'll only have my youth transition service between one and three months.

So I was concerned about how many numbers, you know, my goal for the year basically.

But most of what I'm doing with them is the pre-work leading to them becoming transition for X amount of days.

PAULA MCELWEE: Absolutely, and that's what we've always wanted to see.

But they are at this point inserting this reporting requirement only for post-secondary.

AUDIENCE MEMBER: So I'm clear, ACL is because of this new law definition, etc., is in the process of redoing how we will be reporting to them to some degree, and that that will be clarified so that we're making sure staff is reporting correctly?

PAULA MCELWEE: Let me give you a little history lesson real quick.

So what we have been doing is a 704 report.

Our national presence in NCIL has been looking at that report for some time and asking the question, is this report even useful?

And they have some great ideas cooking around what they would like to see the report become.

And out of the blue a couple months ago now, ACL came forward with a sample report.

It is out for comment now, and there's an asterisk at the bottom of the first page of this, and I hope you will comment because it is not yet decided.

If there are things you think ought to be reported that aren't, look at that link.

It hardly changed at all.

All of us as advocates were hoping to see something that would give us more meat, more outcome-related and less demographic- related information.

And then their sample came out without any input from the field.

Now they're asking for input on their first draft, and I think it's your responsibility and mine to comment on that.

Anybody can comment.

It's open to the public and the link is in your presentation.

But that's hard, isn't it?

The fact, on the call for that report for the new PPR for centers, they said it was going to include reporting for this current year.

One of the comments needs to be, I cannot change what I've already collected for this current year.

I can't go back through all of my files and collect new information from all of my people.

And you expect me to have that done for this current year and that's the report you want next December?

Whoa.

So that's a big concern for a lot of centers.

If you're small enough that you can have everything right there, it's not so scary.

But if you're a big center, it's going to be extremely difficult to tease out the new information for this report.

It's there for you to look at now and you could make changes and the database programs are making changes.

SIERRA ROYSTER: There was a really good question, ACL, Administration on Community Living.

Please keep reminding us if we fall into acronym language.

Administration on Community Living.

PAULA MCELWEE: It's scary.

Sierra has more examples.

Lets see how you do.

SIERRA ROYSTER: You guys never answered the 504 one and we went down a rabbit hole.

We're going to come back out of the rabbit hole now.

I'll give it to you again.

I think this was her question in the back.

Student in post-secondary wanting guidance on moving out on their own who had a 504 in school.

Where do they go?

I didn't give you an age.

If they're under 24.

Transition.

If they're over 25?

Independent living skills.

PAULA MCELWEE: Let me ask a question.

Do you see a way to make this seamless?

So they were in transition services in school that were funded by VR.

They left school and we're assuming a 504 person probably would have also been eligible for an IEP or they may say they were.

And then they're going to age out of that transition program into regular services.

If someone is still continuing to need goals met during that critical time in their lives when they're moving into their full adulthood, it shouldn't be that they have to know where you're categorizing them.

They should see this seamlessly as their process for meeting their goals.

That's an important thing to remember.

And like I said, you can call your programs anything you want.

Do what communicates to your people.

You do not want them to be caught up in this rabbit hole is a good description right?

In the rabbit hole that we have all been kind of wandering through this morning.

They should not have to figure that out.

You figure it out for them and you report it.

Because that's not at all related to their independent living.

It's just bureaucracy to allow you to do the other services.

AUDIENCE MEMBER: I've said when this was first coming out, I said that it doesn't make sense.

Nursing home transition, school to secondary life transition, it doesn't make sense to call it a core service, because it's really not anything different than what we would do for anybody else.

And I think this really brings that out that it's a target population in both of those.

It's not a special service, just who we're targeting to receive the services we already provide.

PAULA MCELWEE: It absolutely is all about how you report it.

The rest of this conference is about providing good youth services.

But one of the foundational questions was, how do we interpret these regulations?

So we put that up front so we can get that out of the way.

But the rest of the conference has to do with youth services.

This part does have to do with how you categorize it.

SIERRA ROYSTER: A famous Jim Baker quote from Septembers I think IL Conversation, is youth are a population and not a service.

I have repeated it probably 100 times.

I'm asking for your permission now.

That's something to remember.

These are services.

And like you were saying back there, you are going into school and prepping them and giving them the skills that they need to graduate.

If we wait until they're in post-secondary education to teach them all of these independent living skills, we're not doing them justice.

We're not doing our job to provide independent living philosophy and add them into the movement and educate them to be independent if we're like regulations say I have to wait so I'm not going to serve you.

Maybe you have served them by providing information or referral because you haven't had that before.

But let's not get caught up.

I know we keep saying that, but this is the box that you check.

This isn't the conversation that you have.

Just when you're having the conversation, make sure that you know when their birth date is, how old they are, and whether or not they had an IEP or 504, whether they were eligible for one if they were home schooled.

Ask those questions while you're having the conversation and then let's get on to, what do you want to learn?

We can bog down on it here, but when you're with the youth, make sure it's all about them and what they're wanting to learn and you can figure out where it goes in the categories.

PAULA MCELWEE: We have a question here.

AUDIENCE MEMBER: To add on that, they have to admit that they have a disability.

And you know, I think the problem with youth is they want to be together in groups.

We just need to find a way to get that.

I know I'm jumping ahead.

PAULA MCELWEE: But you're absolutely right.

We are a community, and I can't say that often enough.

Sometimes we get bogged down in the service delivery part, and we think oh yeah, we've got to do all of these technical things related to service delivery, but we are first and foremost a center for independent living where people with disabilities come together to advocate for things in their community or in their own lives and to work on and provide support to each other as we develop.

And we should not see ourselves as case management and service delivery.

Because as soon as we get hooked into only case management and service delivery, we have lost the key thing about our movement, which is that we are a disability rights movement.

We are a community of people with disabilities who work together to accomplish things individually and as a group, but we work together to make it happen.

It should be a brand name.

I wish that independent living was a brand name.

Cause I heard somebody telling me all about her mom moving into independent living where she has 24 hour nursing care and I happen to know that it wasn't independent living.

We need to make it a brand.

We need to be able to say that.

If any of you are in a service delivery mode, step back a minute.

Because I think that that does happen.

Centers get so tied into the service delivery mode that they forget the rest of it.

If you have forgotten the roots of independent living then that's scary.

You need to know and understand the history and philosophy.

Let's talk just a second about the other transitions and Sierra has a question for you.

She has a question first.

AUDIENCE MEMBER: I wanted to ask about people with mental disorders.

I know that's one of the things we don't focus so much on.

How do we address those youth?

Do we send them to centers that only address people with mental disorders, or how do we help those people as well?

PAULA MCELWEE: With any group, let me say this first, with any group, there is within that group of people who have that disability a wide range of what they want and need.

So the first thing we need to do is find out individually where do they want to go, what they want their life to be.

It is one of the things that might be related to either diversion from an institution or getting them out of an institution would be the transition piece.

So as a group, centers for independent living do not believe in day programs.

We do not believe in sheltered workshops.

We do not believe in institutional care.

We believe individuals should have the right to live where they want to live and live their lives in the community.

So if you start with that assumption about independent living, our history and philosophy, then you realize some of what is happening in your community is institutional and you need to help people get out of it.

Atlantis the civic center that is based here, started because Colorado came up with a new concept, and everybody was so excited in the early '70s of nursing homes for youth.

Wouldn't that be wonderful?

We could bring all of the young people, young adults together so they don't have to be with the old people back in their home town, and we could have nursing homes for them here.

And a young man named Wade Blank went to work there and as he got to know people he knew they needed to be someplace else like their own place in the community.

And he promised a man who was very ill, he promised him, I won't let you die in this setting.

We will let you die, we will make sure you die in freedom.

And ADAPT and the freedom logo came out of Atlantis as they were looking at ways to get free from institutions.

So that part of transition also applies to youth.

Hopefully we don't see it happen very often anymore, but it does apply to youth who are in rehab, in institutions for people with mental illness, who are transitioning out of any other kind of setting.

SIERRA ROYSTER: We're going to go through an example of that for the institution piece.

An 18-year-old is being faced with going to a nursing home, has finished school, and you are helping them stay in community-based living.

Where does it go?

Diversion somebody said?

Transition under diversion.

Is that everybody's thought?

Can you serve them under youth transition?

That's a good question.

Do they have an IEP.

That's a question you want to ask.

Or were they eligible?

What if they completed a private school and they didn't have that?

Were they eligible for an IEP?

What other kind of questions should we ask?

AUDIENCE MEMBER: Are they post-secondary?

SIERRA ROYSTER: They have finished school.

Would they fit in either one?

Yeah.

So I mean there's not, that's one thing, they can fit in diversion.

If you have a goal for your center and you are rocking this youth transition piece, and this person's coming up to an institution, and you're helping them, they don't want to move there and you're helping them get out, that could be diversion.

So another one.

A 24-year-old wants to transition out of a nursing home.

Nursing home transition?

But it can also be youth transition.

AUDIENCE MEMBER: It depends on the other factors.

If they're post-secondary, qualified for an IEP, if they're under 24, it's transition to independence.

SIERRA ROYSTER: Yeah so you see how that, they can fall in either?

AUDIENCE MEMBER: Can you do both?

PAULA MCELWEE: That depends on how the report ends up turning out.

I think we need to comment on that.

I think that we should not be collecting pure numbers because that then limits you in how much you can say they're receiving all of these things.

If you're only doing numbers, they only want you to count the person in one category.

But, like we can now with adults, some people receive multiple services, so in the demographics of how many people are you serving, you can only count them once, but in the demographics of what services did they receive, you count all the services.

Does that make sense?

SIERRA ROYSTER: So that 24-year-old transitioning out of a nursing home, they don't know how to manage their money.

But they were eligible for an IEP in high school.

They are graduated.

Where can you count that assistance when helping them budget?

In the transition.

Because they're still 24.

But you're helping them leave the nursing home, that was just one skill that you guys did together.

Now if they go over that 25-year-old mark, and then they want to learn how to use a computer before they leave the community, the nursing home.

Sorry.

Then where do they fall?

That skill of wanting to learn computer skills?

IL skills.

So break it down.

When you're looking at something, it's not just a blanket.

When we work with one person, they don't come in and say I want this one thing and only one way and that's what I want.

Very rarely.

Usually they're like I want to do that.

Can you help me do that?

And once they've learned something, I want to learn this, too.

They can fall in multiple places depending on what you are working on.

AUDIENCE MEMBER: In Nevada, I think we have more money to get people out of nursing homes, so we would use that program to get them out of the nursing home, and then once we get them out and independent living, then we can put them in the transition youth services.

PAULA MCELWEE: You can fund their exit from nursing homes with more than one kind of funding.

The staff salary, for example, may be covered under Title VII but all other expenses may be covered under the other.

That's typical.

As long as you know what you're doing and you can describe it to somebody, you can mix and match other funding sources.

In fact, you're expected to find other funding sources.

That's excellent to see.

SIERRA ROYSTER: Okay.

Do we have it?

Questions on that?

Okay.

An 18-year-old is coming out of a juvenile justice center and transitioning into the community.

AUDIENCE MEMBER: Are they post-secondary or do they have an IEP?

SIERRA ROYSTER: Questions to ask, yep.

What else should we ask?

AUDIENCE MEMBER: Are they still in school?

SIERRA ROYSTER: Are they still in school?

PAULA MCELWEE: If one of your questions is, does that count as an institution, the answer is yes.

So any kind of institutional care, juvenile detention, prison, as well as mental health and mental retardation are DD services in your cities and counties where they are institutions which are horrible and I hope most of you don't have any of those left.

But if you do, help people get out of there.

SIERRA ROYSTER: And one person in the back just mentioned, I never said if they had a disability.

So going through those pieces, are they eligible for services under the definitions of significant disability?

I need more coffee.

You know, what is their age?

What was their educational background?

Are they still in school or not?

PAULA MCELWEE: And you mentioned something a minute ago about whether or not people were able to identify if they have a disability.

That is a real issue with this population, because they often have not yet identified as a person with they often have not yet identified as a person with a disability, and that makes it tough because it's self-identification of a significant disability that makes them eligible.

You may have to get creative about how you help them to understand disability.

Because that's part of becoming a part of this disability community, right?

It's understanding that they're part of it.

It's a tough one, but it also needs to happen.

SIERRA ROYSTER: And a lot of you talk about going into schools.

That's the time to start setting that foundation for peer mentoring and support.

Bring in somebody with a disability that may be similar to some of the kids in the class.

Some of the students.

Maybe it's talking about disability history and how much we had to fight to get where we are, and we're still not equal.

Get them fired up.

That piece, they want to join that.

They want to go, that's not right and I've had that happen to me.

I don't have a disability, but I've had that happen to me.

That's what that meeting is for?

That IEP meeting?

I didn't think I should ever go to that.

Tell them how many people had to fight for them to have an IEP meeting.

Show them the videos.

Talk about it.

That empowerment piece, that anger that they can feel about having a disability when they're a young person, help them use that.

That's part of why and this is my opinion, why we need to start younger than 18 or 14 when they're in school.

Because if you want them to identify as youth transition when they come out of high school, then give them a reason why they would want to identify.

Tell them that they have access to employment and they have access to accommodations.

Accommodations is a really big word.

Break it down.

Explain it.

You can get help by all of these things.

Then the playing field is equal for you.

Those things are what really help young people want to identify.

Taking them out of the setting where they're bullied, where they're already segregated into their own classrooms a lot of times, and they don't want to identify with their peers.

Kind of jumping in a little bit of programming, but one of the times we worked with a school system, we went through our whole entire school program, disability history, you know, rights, self-advocacy, knowing your accommodations, all that.

At the end of the class, they said that's great that you taught us these things, but none of our peers without disabilities knows this.

So they actually developed their own project and they went out and educated the history classes in the rest of the school.

And that was something they had to go up there and identify to their peers across the school because they were proud of all the history that they were able to learn and that people fought for them to be in that school and have that equal seat at the table.

Not in the other room.

They can be right there with them.

And those are the things that we can do in IL.

Bypass those regulations and not looking at what chart, what column it falls in.

Look at how we can overcome that piece of, youth don't want to identify.

No one really wants to identify, a lot of times.

But if you tell them why, then they might.

AUDIENCE MEMBER: I have attended quite a few transition IEP meetings.

One of the things that I have found is some parents don't want their children to know that they are disabled.

How do you handle that?

PAULA MCELWEE: You know, it is on the agenda, because that's not a simple answer.

It does need to be addressed, right?

Somehow that whole parent relationship is a part of the mix until the person becomes an adult.

And so, yeah.

You've put your finger on a good one and it is on the agenda, I promise.

SIERRA ROYSTER: Just a thought as I'm walking.

That's where going in and educating the student about disabilities and letting them self-identify, wait, I have that accommodation.

Wait, I have trouble with that, too.

And they go wait a minute, do I have a disability?

And they can go say, hey, mom, what is this about?

You never told me?

It's a reverse thing.

AUDIENCE MEMBER: You know, you spoke about disability and then you spoke about significant disability.

Could you share a little more about that?

PAULA MCELWEE: Yeah, you know.

AUDIENCE MEMBER: I think the centers really get confused on significant disabilities.

PAULA MCELWEE: Yeah, it's in the law, and the definition is in your PowerPoint, and I won't go back through that.

But I think the most practical way to approach it is to say if you didn't have any of these accommodations, if you were living in a time and place that didn't have any of those accommodations, would your disability interfere with your ability to work?

Would your disability interfere or does it?

Does your disability interfere with your ability to participate in your family life?

Does your disability affect your ability to participate in the community?

If the answer is yes, if I didn't have these other supports, I would indeed be unable to participate fully in those three areas, then the answer is that they do have a significant disability.

You don't have to make them say the word, but probe a little bit to what are they thinking about their own situation?

It is tougher with youth, I think, and I'm hoping that we can find some good strategies through the rest of this week for that particular thing.

Do you have any other questions for us?

We've got just a few more minutes.

About ten more minutes.

Strategies for tracking this and how to count it on the 704 report, it really should include your youth activity somewhere.

You should have been doing it all along.

Those of you with existing youth programs have been reporting that on your 704 report and the new report, which is called the Program Performance Report, will take its place but will include youth activities.

I think we've kind of covered some of this, but just as you can count the different services that you provide to an adult, you can count the different services that you provide to a youth.

So if they have a goal of advocacy, you should be counting advocacy as one of their services.

If they have a goal of transition and they fit the rest of the definition, you should be counting transition as a service because that is the way the form and the law is layed out.

And not all of their goals are solely around transition.

Remember if you're doing things around, I think peer support and advocacy especially are obvious.

Independent living skills training is especially obvious.

All of those other core services really are important for their success.

So you will report whatever they have goals in.

Those would be how you report them on your PPR.

And group activities that center on advocacy or peer support can count if they have a goal.

And you can only count them if they have a goal as things are currently defined.

Some centers will have the group decide what their goal is and put that in each person's plan.

And others will use that as a tool to accomplish another goal that the person had.

It does not matter which way you do it.

You can only count peer support if there's a peer support goal.

It should be a measurable objective and goal that they have in place.

At the time a person comes into your center, you will have to ask questions about the demographics.

Their age, whether they are in school or not.

Disability if they choose to identify one or more of their disabilities.

You can actually then put that on your form.

That is all asked on your form.

Unknown is an option for disability.

So if they say I have a disability but they don't disclose it to you, you can work with them a while before they are ready to do that.

But some questions you might also ask are what are your plans and goals for completing high school?

If they are in school now.

Or what are your plans for after you leave school?

Because you need to begin to get a feel for that whole scope and they want to stop and think about it, too.

That whole scope of services.

What are the barriers to doing what you want to do as an adult?

Do you have a significant disability?

However you ask that question.

And were you eligible for an individualized education program.

You don't have to ask them this the way I wrote them, but that's the information you need to collect.

You can do that in a dialogue.

You can ask them for examples.

You can do a lot of different things in the way that you actually ask the questions.

But that's the information that you're required to record about the individual to the extent that you can.

And other questions.

Is it any clearer than it was when you came in the room?

Okay.

Good.

Okay.

Good, good.

I don't know if Sierra has any more questions for us to play with?

What page are you on?

SIERRA ROYSTER: 26.

PAULA MCELWEE: I didn't go that far.

I must have skipped.

25 is just a place thing.

Yeah.

There are other regulations that apply.

So we gave you the actual references.

So if you start on slide 26.

These are the actual citations.

Look the regulations up yourself.

You can copy and save them to your computer so you know what to look at.

What we've been covering today, most of it is in 45 CFR 1329.

CFR stands for Code of Federal Regulations, but if you type in that phrase just like that, the whole thing will pop up for you.

A searchable online form that you can also download.

You can find that.

The other thing that counts is 45 CFR Part 75.

Any of you financial people know that we used to have the OMB Circulars, and if any of your policies are still talking about OMB Circulars, you need to change it.

OMB is the Office of Management and Budget, and they told you how you can and cannot spend federal money.

So the way you can and cannot spend federal money is in these regulations.

And that's what applies us.

There's another format that's global and applies everybody.

This encompasses all of that and a few other pieces.

You have restrictions on lobbying.

You can't do that with federal money and you have to say so and have a form on hand in your office that says you understand the lobbying rules.

You don't have to send it to anybody.

Just have to have it signed and in your files.

And requirements for a drug-free workplace.

Including the federal requirements.

Because you get federal money, that includes marijuana no matter where you live.

I know you needed to know that.

There are non-discrimination regulations.

We hope we don't have to talk about this much in centers for independent living, but it definitely does happen that this can be a problem and it is definitely something that we are still bound by.

So there are federal regulations for non-discrimination and we have listed them there for you.

But certainly independent living centers are bound by those regulations as well.

There is other training on the financial piece on our website.

If you need more of that let me know.

There's also an online class that is taught by Maria who is here today.

Just started right?

Yeah.

Maria Stepanyan.

So you're out of luck for this year, but it will come around again.

But we've got lots of training on all of these regulations.

SIERRA ROYSTER: I just wanted to highlight two of those.

We had a conversation about people with developmental disabilities or intellectual disabilities, mental health disabilities, those are disabilities.

So when you're looking at that non-discrimination law, I'm going to change the word, basis on disability.

We can't say we only serve this group, we only serve that group.

You serve people with significant disabilities.

If they identify with that, we serve them.

Pretty straightforward.

And the other piece, 45 CFR Part 91, non-discrimination based on the age in programs or activities.

So that's also something to think about when you're looking at your ages.

We serve people.

So those are just some things I wanted to highlight for you.

PAULA MCELWEE: Sometimes in your state there will be a different approach to when people can and can't receive services if they're older or younger than the mainstream people that come to us.

But we can't discriminate.

Important to know.

The most common money question that I get from youth, I'm going to touch on this one real quick is, is food allowable?

Everybody wants to know can we pay for food with our Title VII money.

Actually the answer is maybe.

What the regulation says specifically is that it is an entertainment cost, which is not allowable.

So entertainment costs includes amusement.

You can't take everybody to the park and pay their entry fees, unless, amusement, diversion, social activities and anything associated with them which includes food, has been interpreted for a long time to include food.

But the regulations state specifically that that is except where specific costs might otherwise be considered entertainment but they have a programmatic purpose.

I think there are times that you can make that case that it has a programmatic purpose.

But there is a second part.

See it's an and, not a but.

The second part is that it was authorized in advance, either when your budget was approved or by your federal awarding agency.

Which would be your person at ACL that is your program manager person.

That is Elizabeth Akinola or Corinna Stiles or, I can't name them all, Deb Cotter or Regina Blye or Veronica Hogan or Kimble Grey.

AUDIENCE MEMBER: What would be an example of foods that you might be able to provide?

PAULA MCELWEE: So what would the program purpose that might apply that it has to have food?

A youth group meeting?

Can you get the kids to come if you don't serve food?

I think you can make a case that in some cases when you're trying to do outreach to draw in a bunch of people for the first time.

I think you could make a case for programmatic, but remember the.

You also have to have permission first.

You can't just decide to do it.

You have to have permission.

SIERRA ROYSTER: Another example of food with a youth group, as you were just saying.

How about they put together the budget for how much they want to spend on that food?

How about they put together a meal that they want to prepare.

Now you're teaching them IL skills and it's part of the program.

AUDIENCE MEMBER: How about teaching the skills of social life and going out to the coffee shop and having a coffee together?

PAULA MCELWEE: I think that has a program purpose.

Certainly you have to have prior approval.

There's, we're out of time, though.

There are some other non-allowable costs on the next slide.

Non-allowable means, if you're not clear on it, that you can't buy it with federal funds.

that you can't buy it with federal funds.

You can still do it with other funds, but you cannot buy it with federal funds.