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>> We have about one more minute to let people drop in and we
will go ahead and get started.

Welcome to everyone that's jumping on now.

We're just giving it another minute before we get started.

>> All right. We will go ahead and get started everyone.

Hello.

All right.

So good afternoon, everyone I'm Sierra Royster.

I am with APRIL Associations For Programs For Rural
Independent Living.

This is the peer to peer interactive workshop for CILs and
SILCs.

And how did the HCBS final setting rule apply to your state's
IL network?

This a collaboration with APRIL and NASILC.

So we welcome and thank you and joining us today.

A couple of housekeeping things to get started, first when you
scroll over the screen a mini bar should pop up depending on
what device you're on you can find that at the top or the

bottom of your screen.

There's where you can find closed captioning for today's session.

You can do captioning by selecting CC tab for sign language interpreter you can find interpreter on screen and interpreter Doris or interpreter Jen.

So if you are only able to see the speaker make sure you are in gallery view so you can see the interpreter and presentation at the same time.

We will go into screen share at some point during presentation today.

You can make people larger or smaller by sliding the bar in middle of the screen.

Withdrew also have Spanish interpretation.

There be globe and a you can select Spanish.

You can mute original audio and you can adjust just hear Spanish translation.

If you have any technical issues please use chat feature to find word bubble in same menu bar.

Once that is selected you will be allowed to follow along with the chat or add in your comments.

If you would like to turn the chat feature off you're using screen reading to do by pressing Alt H and then if you have a question or want to make a comment, today we are holding this in meeting platform on purpose.

We really wanted to make sure everybody can engage in conversation, ask questions and really jump in to everything that we're saying.

We definitely encourage everybody to join in those Q&A spots during the presentation.

But also if you have questions throughout we definitely welcoming those and want to talk through them.

Please feel free to do that.

For those that are on the phone today that would like to jump into the conversation, or use key strokes we ask you put star 9 or Alt Y on key pad to raise your hand.

We will let you know you can unmute and with Alt A.

And that mute and the mu button on mini bar you're more than welcome join us by video cam if you have that ability today.

We definitely thank you all for joining this again.

(Inaudible.) I have brown hair and I will be facilitating part of the conversation as we bounce from different speaker to speaker and then also helping out with any of the chat questions or anything that we see in there.

If you have any questions feel free to message me and I can help with technical questions and making sure that all the questions you may have are answered today.

So now, I'm actually going to turn it over to Amber our first speaker today to share a lot of knowledge with us.

So Amber.

>> Hi there Syria Sierra, that this is Amber OHaver.

I'm here on behalf of NASILC in a contractor role capacity for today.

And I am an individual with significant disabilities, physical, neurodiverse and mental health.

And I identify as she, her and hers.

And I also am a white individual in my mid 40s, long blond hair blue eyes.

I have a black sort of grayish top on V neck top on today.

And pearl earrings in and I think that's it.

But I have a head band if I didn't say it.

And my hair black head band pulled back very, very long blond hair.

That's my introduction of who I am.

Some of you may recognize me or know my face or my voice or my name just because I have worked in the independent live space for many, many years looking a center for independent living various leadership roles and also with the executive director for the and SILC for several years too and have transitioned out of that role and leading down a path of something new and different and exciting.

So at that I will turn it over to Kathy really quickly here so she can introduce herself and I'll jump back into our first slide.

>> Thanks Amber.

My name Kathy Cooper I'm executive director of the Kansas SILC.

My pronouns she and her.

I am a white woman in my 50s with blond curly slight Emmy curly hair.

I have a multi colored sweatshirt on today.

And my background is blurred.

I send it back to you, Amber.

>> This is Amber.

Thanks, Kathy.

So it looks like our other speaker Kimberly I believe she is here now.

She wants to hop on introduce herself, that would be great.

>> Hey everyone I'm so sorry for being late.

Just kind of been going on today.

So I am Kimberley Tissot.

I'll president and the CEO able South Carolina my pronouns her and she.

I am a white woman with short blond curly hair.

I'm wearing black eyeglasses.

And a black top and I valentine's direction and a and a sign in back.

So happy to be here with you all.

>> This is Amber, thank you, Kimberly.

Sierra, would you mind pulling up our set of lights.

I will give everybody a minute to readjust their screen and get settled here before I just jump in.

Okay.

This is intro slide.

April NASILC peer to peer interactive workshop for CILs and SILCs.

How does HCBS Settings Rule apply to your state IL network.

Data is Tuesday January 31st, 2023.

Next slide please.

We've done welcome and intro.

So the HCBS Settings Rule, this is just a bit of review for those of you that already received some information about or somewhat familiar with or just sort of want to learn more about it initially.

What is the HCBS Settings Rule?

It is federal rule and in the slide which anyone can have access to if they would like to make sure we get those to you if you put a request in chat or email you can find parts of this rule in 42 CFR Parts 430, 431, 435, 436, 440, 441 and 447.

And this rule believe it or not, was issued in January of 2014.

So a really quick easy way to sum up really what this is through sort of its purpose.

And the way I look at it or we look at it is this rule is a

tool for really promoting accessing a life full integrated in the community.

So applicable to all people with disabilities of all kinds. Applicable to all settings that receive HCBS funding in a state for home and community base services funding in state. That typically is federal funds through Medicaid.

And states must ensure all setting that receive this HCBS funding compliant with this rule per the HCBS home and community based services state transition plan by March 17th of 2023.

I will just comment that the compliance date has been pushed back many, many, many times not only because of the pandemic, but also change in administration from Obama to others.

And at the federal government level and it is really sort reeked havoc getting states to really ensure this rule is implemented and that the transition of settings are compliant, has taken almost ten years.

So it is unfortunate, but we all know government doesn't move quickly.

Why is rule needed and important?

States and HCBS home and community based services funded providers are still providing these mimicking institutions violating the autonomy of our peers with disabilities.

It also is important and needed because the rule codifies, puts into law, protections and rights for our peer with

disabilities in home and community based services or HCBS funded setting to expand choice and control over their lives in their homes and communities.

And then Kathy I think you're going to jump in and add amounts bit more background and information to this over what's taken place over last nine almost ten years?

>> Yes.

Okay so I just want to give everybody a little bit of background on the CMS, centers for Medicare and Medicaid services and what they are doing.

They are literally doing site visits.

In '22 and '23 approximately 15 states have received or will receive a site visit from CMS.

Kansas is one of those.

We are slated for March 14th.

Right up there against the deadline of the 17th.

As of October 31st of 2022 CMS completed 7 site visits.

I know since then they have done a couple more for sure and they are trying to finish in these last three months.

But, will they -- so CMS visit selected visit by heightened scrutiny criteria.

Stakeholder identified a meeting requirements for heightened scrutiny.

Away we'll get into that a little bit later of exactly what heightened scrutiny means.

But it's basically when a setting doesn't meet all the requirements or there is concern they are not meeting all requirements.

The site visit team when they come, they visit lots of setting include an assist living facilities adult day care center, group homes, setting that provide day services sheltered workshops, intentional community setting and farmsteads.

And the site visit teams, they have visited like all three categories of the presumptively institutional settings.

Setting same building public or private institution, settings on the grounds of or adjacent to public institution.

And setting that have qualities that isolate Medicaid beneficiaries.

I think a lot of times in the IL field we think, oh, well, you know, it's not an HCBS setting we don't have to worry about that because its not an institution or nursing home.

But quite honestly just in my experience what worry going through in Kansas it has been shocking to me to find out who is providing HCBS services and the settings they are doing it in.

So this has been very eye opening.

Just who they are composed of not only CMS but ACL, admin for community living and new addition staff I'm not sure what that is.

But they also have had state Medicaid staff or state waiver

operating agency staff.

So in your state whoever does that, whoever is the agency in Kansas, it's Kansas Department of Aging and disability services.

So I assume that they will be joining CMS and ACL when they come to Kansas.

The team typically receives a tour of the of the setting review person center service plans and other documents on site and speaks with HCBS beneficiaries and direct support professionals.

That gives you a little bit of idea of what's happening during these site visits for the settings.

So I'll send it back to you, Amber.

>> This is Amber, thanks, Kathy.

Kimberly I don't know if you had anything you wanted to add or tag on to any of that if not I will share examples, just one of one of those type of sites that are red flagged in terms of heightened scrutiny.

>> Yeah.

A lot of times, some review I do want to make sure that folks know, especially if there are going to be reviews in your state.

Some of review are requiring you to reach out to people that are currently living in these facilities.

So you've got to really think outside of the box of how do we

ensure that the rights are being protected and that we're hearing consumer voices.

So I do want to mention a little bit more about that shortly but I'll hand it back to Amber.

>> Thanks, Kimberly.

So I will just say an example of one of those types of heightened scrutiny sites are where you have a nursing home and then on one wing and then the other wing of that same building you might have an assisted living facility.

What makes it sort of the you know, potentially will throw a flag for heightened scrutiny for that potential HCBS site is shared staff between nursing home and assisted living facility.

There isn't much separation between the two.

They might eat all in same dining room or access to food in same space.

Also really staff doesn't understand or distinguish much between the two wings from nursing facilities to assisted living facility and support and treat the individuals in the same manner in the same way without really understanding sort of the difference between the two varying types of spaces that folks are residing in.

So on that note I will have Sierra move us to the next slide.

So Kimberly I don't know if you want to go through

these but I will let you take this on since you already brought the protections of rights

>> Absolutely.

We will talk a little bit about the settings rule and what it has to encompass.

Remember that the setting rule we will get to this shortly is not a service.

And so it is really critical for centers for independent living and SILCs to be involved in plan.

Because you remember saying nothing about us without us.

We should be at the table with anyone or any policies or are created about people with disabilities.

So just wanted to talk about some of the rules that require individuals to receive services and in residential and non-residential home and community base settings.

They do have a right to be integrated in and have full access to the lives in community.

There should be plan in the final rule where people that are living in residential or congregate type of settings do have the choice.

So that should outlined in that the plan.

A choice of services and including self direction and providers.

So a provider cannot just be assigned to a consumer.

The consumer has that option to decide for them.

So the plan has to include information about that.

Choose their residential setting and have a lease or legally enforceable agreement in line with federal or state fair housing and landlord tenant.

Remember that the ADA does not control over housing.

Fair housing act does.

And so making sure that, you know they do have options for requesting of accommodations within the place that they are in as well.

Making sure it does follow the federal and state fair housing laws.

But a lot of consumers are living in these facilities should also have a lease that talks about the rules and what they can and can't do so they have an understanding.

Now in our state, they do have leases.

But this, they can't read the language of lease a lot of times because it's not done in plain language or easy reader or any language that is understandable to anybody besides attorneys.

And so that is something that we need to ensure these lease agreements are in language that is accessible for individuals.

Choose service they receive during the day where they receive service including settings are not only for people with disabilities.

So we don't want to house just people with disabilities in one setting in the community or in housing.

And so do they get the option of going to the malls going to church, going to be with peers without disability.

Privacy respect and dig knit.

Particularly in the home including the locks on their doors, entrances do they have a locks on their bedroom doors?

I know that we had some issues at one time in our state where there were cameras that were in the bedrooms and hallways and the living areas.

And so that definitely an issue privacy and respect ask dig knit.

Imagine having cameras on you at all times in your house.

Then just freedom from undue influence or any type of restraint, seclusion, making sure they've got that all in the plan.

So the plan has to cover to make sure that not only folks are safe but their rights are being protected at all times.

>> There was somebody that had a question, they had their hand raised.

Go ahead if you have your hand up.

We can't hear.

You're still muted.

>> I'm sorry.

>> There you go.

>> I wanted to just quickly ask Kimberly, the quote that you said before you got into everything, can you please repeat that when you're

>> Yes.

And so what I sent was nothing about us without us.

So rules will, policies, any type of laws if it's about people with disabilities we have to make sure that people with disabilities are included in these, at the table included in the direction of the policies.

So as CILs and SILCs we are supposed to be led by people with disabilities.

So critical for us to be involved in this process but an also ensure rights are being protected with people with disabilities but also including our consumers in these conversations

>> Thank you so very much.

I appreciate it.

>> Yeah.

Just a clarification for everybody.

So the slides and the recording will be posted to our website along with sent out afterwards to everyone that registered if you were on this call you had to register to get in.

You will get a copy of the recording along with the slides.

So no worries you will get this to you.

>> And then Sierra if we could go to the next slide as well.

I always think of the home community it is for the state that you are in, also think of it kind of like an IEP an individualized education plan for students with disabilities. Where it outlines everything how a student's rights would get protected.

It is similar to that as with HCBS settings the rules are exactly it should layout how people are having their rights protected and ensure they have dignity and respect and ensure they have privacy ask all of that.

So that's really important to make sure that we think of this more as a rule and it's not a service.

This is not a service.

HCBS is service.

That will be explained.

Rule also requires to have the option to live alone or select their roommates.

I don't know if you all remember college days, not being able to select your roommate could be really, really rough, right?

Well staying with folks living in any kind of residential setting, they do have that right to select a roommate.

If they are not compatible they should have right to act to move to different location or request another roommate.

So that needs to be laid out as well.

Decorate and fill the home with furnishings they like.

I know, in South Carolina this was not an issue for a lot of

our folks they got to choose the color of the paint for their bedrooms, their bedding they could choose their bedding everything kind of in the house.

They could decorate as they wished.

That should be the case for people.

Because it's essentially their home.

Control their deadly schedule and choice daily life activities.

And so this was an area that we saw a lot of concerns in South Carolina where they had scheduled outings.

So it wasn't the consumers that actually got to pick where they went.

It was the providers that got to pick.

And if consumers did not want to go out on an outing they were they could not stay home alone.

That was one the issues that we reported.

Control or back access and prepare snacks.

Snacks are important.

I know I had a snack before I got on.

That is important for everyone.

Being able to access it food what your choice is and get to decide what menu looks like is really important.

So again the rule has to layout how all of this is going to be.

Access and prepare food or work competitive integrated

employment.

So remember, I know that Kathy mentioned that sheltered workshops are considered a congregate setting type.

It's where people with disabilities are only put or only housed together and they are working on, working some meaningless tasks and getting paid less minimum wage.

So making sure consumers have the option and should have the rights in your state to work in the community.

That is competitive and celebrated with peers without disabilities.

And so in South Carolina, that was easy for us to put in our plan because we just ended the minimum wage last year.

So that was thing we're already ahead on.

That's not going to be an option to work in these congregate settings.

Physical will accessible and reasonable accommodations and making sure that consumers have that option to request that or if there need if they are not able to be independent in the setting of their choice.

They should be also able to receive accommodations to make them more independent in that setting.

Again, just control and manage their personal asset and resources and having that option.

A lot of consumers in South Carolina did not even get that as an option to be able to control their finances.

And so it was automatically really essentially taken from them as soon as they moved into a facility.

Now I will pass it back to Amber.

>> This is Amber, thank you, Kimberly.

Sierra if you could jump to next slide I think it might be Q&A time.

Nope, I'm wrong.

One more slide to go.

So the HCBS Settings Rule, again what is the IL applicability?

How is has relevant to independent network and CILs?

So basically a lot of what we already said really driven down into, you should be picking up on the fact that this rule really does support the IL philosophy.

It supports true choice, control autonomy of an individual.

Supports authentic community living.

And supports the work that CILs have been doing for decades.

This a part where we really want to mention and try to clarify that.

What rule is not is a service.

So it really justice a way to support all the work that we are doing in terms of HCBS service and continue to do as CIL and SILCK in our states and communities.

It allows us to actually be able to leverage a lot what now in state law when it comes to these rights and protections that

all of our peers are guaranteed and supposed to have and need to have.

Because the law says it is so.

So the one thing I do want to the also point out is that this rule does not apply to nursing homes or skilled care facilities.

Intermediate care facilities for folks with intellectual and developmental disabilities or IDD, and mental health institutions.

I don't know if Kathy or Kimberly you want to add anything else to that?

If not I think the next slide is where we jump into Q&A and engage in some conversation with folks here today.

>> Go ahead Kathy.

>> Sorry.

This is Kathy.

So I will say that I have seen some questions in the chat.

We will get into like what role does the SILC play and probably more about what CILs can do as well.

We will really get into the weeds on that kind of stuff as well.

>> I know that in some of, in our state we really pushed back because community residential care facilities, which are smaller assisted living types of facilities are not really recognized as being a set being for final rule.

So got some push back and advocacy that our organization has done to ensure that the voices of people living in these community residential care facilities are included.

But our state does not recognize that.

But these are more smaller group homes that people should have a choice to live in.

So in our state we call them community training homes.

Sierra, do you want to jump in do you have a question to pose to the group?

>> Yeah.

>> You can also kind of start jumping in do some conversation that way.

And then before you do that.

I have a question.

If we could get sort of maybe an idea from folks, would you prefer to have the conversations with the screen share off so we can see each other and engage more effectively with each other and have a discussion that way

>> Yeah.

>> Okay.

That would be cool.

>> Does that work for everybody.

Then we can pop them back on.

Okay.

>> Yeah.

Sierra, go for it.

So I just want -- all of us really wanted to know what ways are you all within your SILC or within your CIL are you aiming using the HCBS settings rule within your work?

How is that coming into any of your work or what does that look within your organizations?

Just because I know a lot of people joined, this will be your encouragement. Star 6 unmutes you if you were on the phone. And also if you like you can raise your hand.

So is anybody doing any of this work within your organization with HCBS Settings Rule?

>> So this is Kathy with Kansas, again I just want to make sure, you know, this -- don't feel like you should, hopefully people are starting to talk about this and understand this. But quite honestly until I heard about this I want to say probably back in May of 2022, I wasn't involved in.

The Kansas SILC wasn't involved in it.

I think this is really just started to gain momentum because ACL has put out the contracts and asked for different groups to come together and work on this.

So don't feel like you are like, like you should have all of this stuff.

Kansas has stuff but it's only because we're getting ready to have a CMS site visit.

But honestly, some people are probably going to be pretty new

and pretty fresh on this.

So just keep that in mind, it's like everybody else doing or anything like that.

So please feel free to ask any questions.

Get any types of clarification.

>> In the chat before sill organizing a work group around barriers to LTSS and personal care assistance to add to our next SPIL.

So sounds like some work is starting there.

>> Yeah I just wanted to add off of Kathy, too I know that when these work groups got started in South Carolina, it wasn't, it was really within state agencies.

So the state agencies really came together.

You have to kind of push your way into sometimes those work groups.

And maybe building that relationship with the Medicaid, with Medicaid department within your state.

And I know that's what we did.

We were invited and we also had the other centers for independent living in our state included as well.

So we were at the table during the planning of the our final rule.

We got consumer stakeholder input.

And really added value.

I believe you know, just from observations of the work group,

just Centers For Independent Living we were really only ones that were pushing, pushing consumer control.

Because person center is somewhat different.

But we were really going a step above person centered with consumer control to really ensure that consumers are at the table and leading this.

You may not have been invited.

But sometimes and sometimes advocacy work in all of us we have to wiggle ourselves to be involved at that table.

>> In the chat too Carrie England said, in California most of efforts have been at the CIL level as the SILC we are discussing but honestly I think more info why I'm here.

I do have LTSS group which I will take this back to.

And Brooke says the Oregon SILC and CILs they had an ACL premeeting for the HCBS Oregon site, but it is scheduled for April.

>> This is Amber.

I just wanted to say, I wish so very, very much now, I would have been more familiar with this rule when I was working at a center for independent living a handful of years ago.

It would have given me so much more credibility when I said to a provider, yeah, you can't have camera in this person's bedroom on 24/7.

Real situation.

It would have given me a lot more teeth.

It would have given me lot more opportunity to say, the rule doesn't allow this is this is not okay.

And this has to change.

So examples like that I'm sure those of you from CILs here today experience a lot of violations of all the various rights and protections.

Probably on a daily basis with your consumers that Kimberly went through.

If you guys have some examples of those to start talking about, that would be fantastic and maybe that's a good place to start engaging the conversation.

So if you've had situations where you're working with someone and transitioning them out of a nursing home and getting them back into the community but maybe the assisted living facility they are looking moving in doesn't have locks on their doors. Or yeah I can only have guest from this time to this time during the day.

Or no one on Friday evenings or any of those kind of things. The list is probably endless quite frankly in terms of all violations and rights and protection that is we went through that a lot of our peers experience in these settings.

So maybe if you want to share some of those examples or what you've witnessed or what has happened to you or any of your fellow folks that you know are issued in your state going on in these settings.

>> I see there is a question in the chat.

A person asked I hope I'm understanding correctly.

CMS are making in person visits to states regarding HCBS.

This is a listing when and where in the state CMS is visiting?

>> That's a great question.

Yes.

States are visiting and coming to states for these what are called heightened security visits that Kathy mentioned.

Kathy, I don't know if you want to dig into that a little bit more and respond in addition to that.

But yes, I don't believe they will occur in every state, but I know they are going to hit quite a few of them and already have.

Indiana has been one.

I know Kansas is coming up.

Kimberly had a heightened security visit from CMS in South Carolina.

So you know, they are happening all across the country.

Go ahead, Kathy

>> Yeah.

This is Kathy again.

So to my understand only 15 for 2022 and 2023.

So 15 states total.

There could have been some states done before that I'm just not aware of it.

Again, you know IL is really coming into this late to the game.

I know in Kansas a lot of when I first heard about this I started asking around.

I asked my centers I said hey, there a group put together for this?

Who meeting on this.

And quite honestly answer that I got was oh, well, yeah we went to like one meet thing but we're really just letting the IDD group take care of that.

So I think that's what why ACL pushed this out on saying we want to go way more stakeholders involved.

We want to get more IL involved because they didn't want just to be a few select groups who were working with stakeholders on these settings rules.

So I don't want to go into it now.

I will go into it about Kansas and how and what we have done and SILCs can work with centers and all of that I don't want to jump gun on too much off that but not all states have had this, but you will see more and more states.

They are coming to your state.

If you know who your agency is that works with CMS on the HCBS stuff, that's how you can find out if they are going to come to your state if they have or if your state has turned in transition man, if there were any heightened scrutiny settings

on that plan or in that for your state.

That's really a key.

>> I just wanted to add real quick.

CMS is scheduling these are visits and what Kathy said in 15 states so far scheduled for last year and this year.

And what is happening ACL is then saying we want to do a premeeting.

that's what Brooke mentioned in the chat.

They do a prep meeting to talk about how can you highlight issues who are partners all of stakeholder and partners on that prep call to get you all aligned so when that call does happen, you can all be there to share that piece, share any information and all of those kind of things examples any particular sites.

But then CMS will come and do a site visit.

They will give you the time, the day and time they will be there.

They won't tell you where.

They kind of do that on their own.

That's not something we go to.

So that is no the where IL you come to if that first call with CMS and you kind of guide them on some issues that are happening within your state.

That's where we get that guidance and that is where really impactful.

I will say NASILC and APRIL are part of some of those stakeholders so our job within this is to educate everyone on this but also to push that information to make sure that CILs and the states are on the calls you're getting that information from us.

And then we're sending you maybe some prep information, you can also reach out to us SILC and APRIL to ask questions to prep you for those calls if you have more questions or want to know some of those partners.

That's kind of our role to make sure that we're getting all IL to the calls so you can make sure your voice is heard.

If you haven't seen it already.

We did just do this in October.

Amber has this in the PowerPoint later on that will be sent.

I'm going to drop into the chat as well so you have it in multiple places.

But there's a list of where they've already been and we will talk more about the reports in a little bit.

But you can see if they've come to your state.

If your state is not on there they haven't come yet.

You're probably, you might be coming up sooner or later.

>> In South Carolina when we had our CMS it was actually in South Carolina last week.

And we helped CMS kind of learn the issues that people with disabilities were experiencing in these settings.

So we did some prework, some surveys out, we did some interviews with consumers who really represent the consumers so that when CMS comes they know what to ask folks. They know where to find individuals that are having significant right issues.

So I really took that as, you know a really proud moment for our organization.

Because we got to really do we really got to bring the concerns that consumers around our state are experiencing. And really make insures CMS looks into specific issues so we can make change.

>> Before we move on I know you all are going to jump into examples.

I think this is really important question.

Could you distinguish between consumer centered and person controlled for those not familiar with the two terms?

>> So this is a hot topic especially in the world of social work.

So MKW, BSW or always talking about person centered.

Person centered when you come to a table and the and the person who you're working with is there with you and there are folks around, different providers that providing input.

But individual is posed to be taking charge.

What we see in person centered planning is, it is a team.

It's a team of providers, family members, whoever they want to

be there.

So they do get that choice of who they want at the table.

But we often see having people ideas put into folks to make those decisions what others want of them consumer control is what Centers For Independent Living practice.

We're all consumer driven.

And that is step up from person centered.

so person centered the way I look at person centered is it's okay. But we really are trying to aim for consumer control where consumer leading meetings and they are telling you exactly what they want for themselves.

You know you could absolutely provide some support in those meetings they should utility ultimately making the decision and even setting the agenda for the types of meetings.

I think we're all aiming for, you know consumer driven.

One time it will work person centers as of right now until we can continue to push consumers to truly have that control over every, every day.

And a great example of that we've seen in person centered planning is maybe a parent will be at that table.

And a parent will say, well you really like it in that sheltered workshop you go to.

You have friends there.

You get to color and you get to paint your nails you really like it they are like oh, yeah that's great.

But they are not having those they are not leading those ideas or that discussion.

So that, so person centered can be it depends on who leading the person centered practices.

But that is not what Centers For Independent Living should be practicing.

We should be getting information from our consumers.

So hope that made sense

>> The way I describe really like consumers directed.

You're in the driver's seat.

You are driving that car.

Driving the choices, driving what happens for your life.

You are in control.

And person centered I tend to say well sometimes you're in the back seat.

And sometimes you're in the back, sometimes we find people in the trunk.

I mean that in terms of folks are there, but often the person with the disability is not very much engaged or involved and getting to actually really determine how they want their life to look move forward in terms of the services they receive and where they receive those and where they live and if they work and where they work.

The list goes on and on and on.

Is driver's seat versus passenger seat, back seat.

Easiest way I can describe it for folks to sort of break it down in that way.

And that just sort of helped to distinguish that.

What you will find in lot of spaces outside of independent living is that folks social worker in particular and some other individuals and providers will use the terms inner changeably.

And they are not the same.

They are two very, very different things.

Support by different philosophy and sometimes even different values and ways of thinking and beliefs.

So I'll leave it there.

Looks like we have a question.

>> I was going to say really quick before we go to the questions, there was a question in the chat that we're going to get how can CILs or SILC get involved.

We will get to that.

But one way SILCs and SILC can be an at in process.

When meeting and they talk about person centered plans people from IL tell me more about that.

How is that being done.

Who is leading that.

And we're starting that conversation and asking those questions to make sure the person with the disability at the meeting is for and about is also leading that meeting.

Before meeting a meeting ever happens we're already doing some of that advocacy work on different stakeholder groups.

That's just one way to do that I do see a hands up.

Go ahead.

>> Hi I'm systems change ad in California?

Snell valley.

Through for holding this meeting.

Because I hadn't I have no information on like, come again, tell me more.

But I clicked on link you provided and California is on the list.

But okay, so now we know that California they came to California already.

What when what does that mean with the letters and stuff, is initial approval addendum is that where the state provided them the information and let them know what they need to do?

>> I was going to say the lining posted actually the third column California doesn't have anything.

So you have not had one yet.

That's where it when we're talking about the visits that third column.

>> Okay.

>> Sorry.

>> This is Amber.

What that link was really nice and also going to be in

PowerPoint presentation, you can access link from there too as well.

That link takes you to page you will find every single state listed.

Right?

Every state requires to have an HCBS state transition plan.

In is to that, it will list all of the various steps and all the different types of addendum and changes and initial proposed plans over the last nine years that have happened for that state.

That is typically like that middle column.

And then the column that Sierra mentioned one furthest to the right that third from left over column, some states will have something this in there if CMS has come to your state and done a heighten scrutiny review and they have completed and finished the report of that review to that they came and did. And in that report it will list all the various sites that they visited.

And then what they found was out of compliance or in violation of the rule.

And then suggesting, you know corrective action plans and changes the state has to submit to CMS about how they are going to work with those setting and there were issues found or sites were cited for being in noncompliance with the rule how states will work with those settings to get them in line

with the rule and in compliance by March 17th.

So that is the just a gist of that page.

Combination of all the different states transition plans for every single state and all different steps and information and back and forth communication from CMS for those states.

And then on the other far right column are those heightened scrutiny reports if they've done and have posted them, you know, turn around time is taking about six to eight weeks for them to get a report finalized and sent out to a state.

So just sort of a time frame that we're looking at.

Which is actually pretty quick quite frankly for CMS.

Hopefully this a helpful in terms of describing that page.

Kind a mix ever different things but that where everything is housed through CMS that you can back set.

>> And you can look at your plan for your state and the see who, what organizations were involved.

So that's really important to look at.

I know in South Carolina, it does you know it does have our organization task force and so that's really important.

But if you're missing you're feeling like you are missing from table make sure consumer led organization are at the table.

And that you can something you can push.

>>>

>> So this is Kathy.

This is where SILCs come into play.

I found out about CMS coming to Kansas because ACL reached out and said who should be on the call for this?

Because ACL and CMS will specifically CMS they didn't know.

They didn't know who to ask for this.

They reached out to SILC I said well you will need group, this group this group and this group I was able to send them contact information.

The project that ACL is doing with CMS that involves national stakeholders ACL is doing pretty good job of reaching out to national stakeholders and asking them, hey if we're going to just picking a state here, Texas next who should we contact? And then those stakeholder groups can say oh, well we know that the person to contact for the Texas SILC this is person. And then from there, you know, the SILC can help them say oh, well here's the centers, here's the protection and advocacy agencies.

Here's the IDD council.

Here's, here's everybody you should have.

That's how it worked in Kansas.

And like I said I had no real idea what was going on in Kansas until I really are started doing research.

I went on state agency site who handles home and community based services.

I literally just typed in a search on that page that said HCBS settings rule.

Low and moldy up pops a whole other website completely dedicated to this.

It had the HCBS transition plan for Kansas.

It had all of the providers that were receiving HCBS services.

It had the ones that were going through heightened scrutiny.

It was quite a knowledge place to go to learn about what was happening in my state.

I encourage SILCs to first start there.

Find out who at agency that does HCBS in your state.

Hopefully you know that all right.

The whole reason we have ex officios on the board is they are supposed to be that disability agencies not just any other disability agencies you have in your state, you know if you're utilizing it correctly you can have an ex officio on your SILC for that.

In Kansas we do.

We have one electric Kansas department aging and disability services.

That's another option that you have to go to find out what your state is doing if they've already been approached by CMS, if there's a group already together.

I signed up for the list serve.

Got on that group through that state agency.

But then also contacted some of my centers and said hey, do you know about this, what's going on.

The next thing that really kind of happened was when ACL said who should we contact in Kansas and I gave them a list of people.

They contacted those people and they said, CMS is coming, when can you all meet.

And it is this ACL before meeting.

And ACL has great.

They've come in and said he's what you can expect.

They've been very kind of frank about the things that CMS is looking for and how this works.

It's been actually pretty refreshing.

But they came in and they told us here's what is happened in other states.

Here is what CMS has found in those other states.

Here's what we encourage you as your state coming up for this to do.

And Amber is it okay can I just roll into what we did?

>> I kind of am

>> Go into that.

But I think Sierra you be pop up that slide for one minute that kind of really speaking to exactly what we're rolling into here describing SILC and CILs how we get involve and engaged and on this rule.

That what we're really talking about will engaging as SILC and different ways you can be involved in your state as a SILC and

CIL or and rule ties and supports all various types of I guesswork in these areas.

Which is for SILC systems advocacy and collaboration of partnership development.

Then for CILs we really look at from an individual advocacy and systems advocacy perspective.

And also really tied nicely into supporting the division related service and divisional related service.

At times, also, outside of that, some other CIL related services like youth transition and some other different types of services that I'm sure Kimberly can hit on.

Sorry, Kathy, back to you

>> No, no I knew I was skipping ahead I didn't want to do that but it just felt natural to just go on with it.

But here's where SILCs pivotal.

You need to be the one to make sure that all of the, you know certainly all IL network is involved.

But also those other disability partners in your state are involved as well.

And chances are some of them are already going to know about it.

But, you know in Kansas, we got together as a group and we met ACL.

We talked about a lot of different things.

Group just instinctively started to bring up issues in Kansas.

Like oh, what about this.

End what about, you know the videos and we had a provider in Kansas that is I mean they just basically brag about their control room that they have with all of their video options where they can watch people in their homes and their setting and they really sell it as this huge safety net.

And of course we come in there we think we're horrified.

Think oh, no.

Who would want that?

What a violation of your privacy and your rights.

So then we start asking whole bunch of questions ACL is well, you know good stuff.

They really kind of helped us determine what, how we can bring this to CMS.

Because CMS will come to your state and spend one hour with you beforehand before they come do on site visit.

They helped us set up that call.

After ACL meeting our cans group got together.

We ad even more people.

It's a phenomenal group of different disability organizations that have now come together that is bigger than any other coalition or you know work group or whatever that we have already.

And it's from all different types of disability setting and services and everything.

And we had two-hour meeting recent will.

We set up several.

We said okay, what are our priorities.

We have to be concise.

We have one hour.

And really the main point of that one hour is to hear from consumers.

And so, we had to integrate that into it too.

Providers we like to take control and do the talking, but it was really important that we pushed consumer parts of this.

To hear from consumers and their voice.

So some of the things we've worked on in Kansas, the points to get across to CMS in our very limited time on the phone call, because they, they probably have a listing of you know Kansas isn't big population wise.

Five or six settings that they will see.

Most of time CMS is going to at least two different areas of your state.

Some the bigger populated states they are gone to like 8 different places.

In Kansas I have to assume probably going to go to four or five.

So we said what most problematic examples of assisted living everything talks and goes through experiences and list some stuff.

We said, well what are the most problematic examples of day service settings.

Again the whole conversation happens.

And then the and a most probable residential service and fliers provide more than one service.

And most problematic example of use video monitoring that is again agency SILC I had no idea that was happening in our state.

It's been a long time since I worked at a center and have had boots on the ground and provided services.

A little disturbing to hear about things are seen as progressive by certain providers and what they are doing.

But, the CIL being really can have the role in facilitating this group or they don't have top our P & A took over and did all of that.

But we provided, you know what we can do to help bringing in centers and if you think about this, SILCs part of their responsibilities and authorities.

Coordination with centers coordination and collaboration and partnerships with other disability organization.

That's truly what this means and why SILCs should be involved.

You can put stuff in your CILs.

Quite honestly Kansas doesn't have something specific about HCBS settings rule or HCBS transition stuff.

But I guarantee we will in the next one.

That's another way that SILCs play a major role in this taking look at that and what your state is going to do.

So Kansas we have our meeting with CMS over phone on February 8th.

And then we will have our in person site visit on March 14th everybody is supposed to be reading study rules by March 17th.

But, you know what do I do now?

What if they've already come to your state?

Well we have to be continuing this conversation as that collaborative group for future once they come to your dissipate they say oh, here are your issues.

They will give you list of things that will change.

We need to make sure our state is changing those and our state has the staff to do that.

In Kansas, we have lost well over 50, 60 percent of our state staff that would go out and monitor this kind of thing.

So that's where SILCs come into play.

This systems advocacy.

You can push for this and say why it's important, bring this up at your SILC meeting and talk about it.

I know I saw hands I want to make sure we get to the questions.

If you have a question, you can go ahead.

>> This is Amber.

Rile just add.

In Indiana this was an unfortunate situation there was a member of another organization that really was bringing different groups and entities together in our state all of your players, you know, that Kathy talked about also including our ombudsman AARP state-wide chapter and organization. And a handful of others.

What was really the discouraging to find out from ACL at one point in connection with NASILC is that independent living as a result of sort of this leader bringing this group together was I hate saying like intentionally left out, but the individual was very much aware of independent living and very much aware of me, the SILC, the CILs.

And so sort of scrambling last minute, right to get involved and engaged at the SILCK level was really tough.

I had to make sure ACL was aware and knew to please add the SILC in our content information to that list any kind future engagements and opportunity to do this work and get involved. So I hope many of you are or all he have you don't have to experience those kind of things in our state, but you know, I'm sure we've all encountered times where different groups and organizations can somewhat territorial and it is extremely unfortunate that happens.

So just if that has occurred oh are is occurring in your state reach out to your project officer at ACL or NASILC or APRIL or and we would be happy to get you fully connected right to the

right folks to get engaged in this space with the other organizations and groups and entities that are sort of already engaged and working know various states and not against each other because, that is not going to ultimately help any of our peers so better together.

Making sure we've come together despite some of our differences we might have knowledge.

But like I am pretty sure all of first making sure very things we're talking about in emergency rooms it of rights and protections for our peer with disabilities is something we all are behind and will continue to be a leader for.

Not only when it comes to independent living but outside of our organizations.

Just want to add that.

>> And this is Kimberly.

I did put information for folks that are planning or getting site visits and how you can help.

So our center for independent living actually took the lead.

We partnered with other ACL grantees which I really encourage you to partner with, and your advocacy system, your university center for excellence and developmental disabilities, the DD council.

So away partnered with them along with other two centers and we led the conversation.

We also we were also a little uncomfortable with the approach.

Because the approach was to get as many consumers as you could to be part of the conversation to discuss the concerns.

But when someone is being either abused or neglected or when they have concerns about their facilities.

That's probably not the best way to ask.

ask for their input, to have them, with an open forum call with potential providers.

And so what we did is we ended up sending out a survey.

I did put it in the chat.

But we want to get the information in a variety of different ways so we did some interviews folks wanted to call us, we made the process as accessible as possible so we could bring their voices to the table so that if there are any concerns that their rights are being protected and of course our organization was helping them either transition or get other services from disability rights, South Carolina.

So we led the conversation with on the call but we also would only -- let me go back.

We were supposed to provide input from consumers.

But I also know that every state before us really included a lot of provider information.

And also their families that were on the call.

That was heavily pushed as well.

Our state decided to do something a little bit different.

We said, you know this is an opportunity for consumers to use their voice.

So when the survey we collected we did have drop down box who do you represent if you're an individual, if you're a parent. And we only brought the input on the call, of course, we gave everything over to ACL and CMS.

We only brought up the concerns for consumers.

That a parents are vocal and loud in their own way sometimes against IL philosophy.

So we are making sure we bring a voices of people with disabilities.

We led conversation and just some of the input was, you know, we did have violation that is came out with the concerns that we noticed and I'm just going to read something really quick a consumer put to be something they would like to improve, one said to be honest I just want to be happier.

I don't like it here.

Some say I want control over my money.

And so the same things that we were trying to look for they were telling us what they wanted.

They want the rights.

They should be given these rights.

But honestly a lot of times the provider are taking over and not honoring.

And something that we also noticed during the work that we did

in South Carolina, was that the final rule that South Carolina had approved and moved forward, just a piece of paper.

Nobody is enforcing it.

So that was a real eye opener for disability rights South Carolina as well is there's no enforcement to this.

So what can we do as a network of partners that really want community based services in South Carolina.

What can we do to help enforce it.

It was a really wake up call for different steps of not only partnerships but, but other services to improve on and how we can better reach consumers.

>> Thank you, Kimberly.

Sierra, this is Amber, Sierra, can you jump to the next slide.

It might be the one there's well if there's -- yeah.

This is sort of gets to a little bit of where I think Kimberly was going around how can we start to know back and resource HCBS state transition plan report page, that's that number 2 link on this slide.

And the first link though which in know resources.

Is really about, it's go guidance and technical assistance on rule from CMS.

So I'm sure as you can imagine it is not very -- it's not in plain language at all.

I will say it like that.

It is probably language you will have to read maybe over and

over a couple of different times wrap your head around some of the not all of it but some.

It does have some really good information and ways to help sort of, you know, navigate through what this really, really means.

How it can really be of benefit to and all network and just for disabilities and even folks in aging community all various types of disabilities in our state.

There is that resource as well that's a really good one that has like various types of guides and even technical assistance that you know offered to various states across the country when doing this work.

And the other thing to remember is there are was a requirement for the states to come together as a task for and create these groups or work groups whatever you want to call them in your state of various sort of key stakeholder which should have included consumers to help develop these state-wide transition lance.

I know in Indiana that there were not very many, if any consumers engaged and involved in on that task force.

It was very unfortunate to hear that.

Some of those are still working together and coming together and may continue to exist in your state moving forward.

And can shift and called be some different and try to operate as sort of like an advisory group for coalition to try to

monitor and a provide some level of oversight by state in terms of compliance or ongoing compliance with the rule. New no promises, groups were really created to craft the plans.

But hope, fingers crossed this something as SILCs and a CILs to do, and for responsibility of oversight and compliance on plan and ongoing compliance, will you continue an advisory group.

And I might even suggest ask solely consumer based of consumers that reside in these particular type of HCBS settings to ensure that the state actually gets feedback and input from those folks on violations that are actually happening of those rights and protection that is Kimberly went through in the beginning of this presentation.

So if you find in your CILs you're working with consumers and you are fully aware of what rule says and individual's right in that HCBS settings is and are, that is being violated repeated there may be many of them, you know you worked with consumer and consumers even notified these, you know provider and in that setting that this is not in line with my person centered plan, this is happening and this needs to be changed I have a right to privacy.

Right to have lock on my door.

I have right to say who can come and go into my home and my place and where I'm living.

I'm hungry 2 in the morning I want a granola bar.

I want at fruit.

I can't get access to that.

That theory right violations.

All plans grievance procedures or those are supposed to be laid out and pretty transparent.

I would strongly suggest CILs and SILCs dig into those stayed plans for your state and find the section that is applicable and talks about what the grievance procedure is and will be.

If a setting HCBS setting is violating and not remain or staying in compliance with what the rights are, consumers are having a lot of difficulty or issues with that.

You can help consumers file those grievances.

And walk you through what that looks like or, you know you can walk through with consumer what that looks like how that happens to understand that grievance process.

And then who to contact in your state to file a grievance and how to make that happen and then we'll follow through on all of that in terms of an investigation and looking into that grievance, you know what it consists of what outcome will be as far as the state circling back to that particular setting to address any out of compliance or violations of the rule issues.

So I don't know if anybody else has anything else to add to that.

Kimberly or Kathy.

But I wanted to make sure we hit on resources and really one of the best ways I think that all varus out entity, advocacy organizations consumer organizations doing this work involved in state can really make a huge impact is filing grievance after grievance after grievance after grievance.

That is going to get more red flags than anything else.

I strongly recommend folks from SILCs and CILs really dig into grievance process.

CILs with your consumers really utilize and leverage that opportunity you have to do that heavily.

You can I happened to go down that path.

You're so right thank you for bringing that to our attention.

What we fixed and what we're doing now.

I think a lot of us know that is always the typical experience for disability folks in aging community have with some of these providers.

So anyway.

>> Amber I would just warn you do help a consumer file a grievance, don't count on that 100 percent.

Making sure you help them out of situation by you know service that is you offer or connecting with your protection advocacy too.

Don't count and just think because you did file a grievance for the consumer fraud grievance they will come down and fix

things really quickly that process is really, really big.

>> Yes, thank you.

Thanks.

So I think we're a Q&A point again?

>> I'm going to put this towards Kathy for the chat.

[INAUDIBLE]

I know you mentioned that earlier.

>> Yeah.

Some states still don't have final approval on their plan

>> This is Kathy.

Basically a simple answer.

They have enough staff.

To they are only going to be able to do so many every year.

It will be interesting to see since the deadline is March 17th for the nation what they do after that.

You know, if I though they do have some states scheduled after March 17th.

But it will be interesting to see if they take a look at how many states did comply, how many states are still out of compliance.

But that's where your SILCs and CILs come into play you can continue to push collaborations forward and make sure that CMS knows that your state is not following the settings rule.

They did not clean up their act.

They didn't do what they were supposed to do.

One of the ways that Kansas SILC is going to do that first, SILC itself has to be educated on this.

And so one the ways we're doing that is not only just me being as knowledgeable I say possibly can and joining in, you know the coalition and collaborations on this, but we have board meeting I will do like 20-minute kind quarterly training on the HCBS settings rule so board familiar really what this is and what it means to our state and the people in our state with disabilities.

But the push has to be there for the future and holding states accountable.

Our states already told us they have less staff and they are doing the best they can.

And that they have new staff.

And one the things that I did was join the provider call.

So there's two different groups working on this.

It's the very interesting dynamics you have stakeholder groups, disability organizations and they are working on it they are trying to say hey this is what's going wrong, what is happen thing we're hearing this from our consumers and you have provider group who is providing the study.

And getting paid by HCBS to have these studies and follow theses rules and be in compliance. I joined that.

It's public and open to anybody.

It was incredibly disturbing to hear my state tell these

providers, we will work with you.

Don't worry about it, we'll figure it out.

I thought ugh, no.

Hold their feet to fire.

That's what I wanted to say.

But I encourage you to do that too be on every part of this.

Be listening to the providers what they are saying and know and been knowledgeable on that.

Listen to what your state is saying listen to what your disability organization and consumers are saying.

>> I see in chat Brooke mentioned Oregon scheduled for April 17th through 20th after the March deadline another extension.

So they will be continuing past the March 17th deadline to do the site visits we just I think today got notification that Idaho's coming up later on as well.

They are going keep doing some of these site visits just not going to earlier question of only so many people at a time.

I wanted to make sure we can definitely go to questions.

I want to make sure we share this piece as well this has been a question y'all have asked of what can y'all do.

This is what you can do after those calls.

If your call has already happened.

But, even if your call coming your site visits are coming up.

>> This is Amber, thanks, Sierra.

Yeah sort of say just because March 17th comes doesn't mean compliance with this rule is going to continue to be how these settings operate and function.

And just like we ad advocates often have to be enforcers of ADA and other various types of we engage advocates kind of comes down to that same kind of situation and scenario when it comes to this rule here.

So my hope is that CMS does continue to do these, not only after March 17th throughout the remainder of this year, but I'm hoping it just becomes an ongoing or revolving type of practice they do on a regular basis every year to ensure they visit states and talk to the various groups and providers in these settings to make sure they are still remaining in compliance and operating as such.

Because between administrative related changes, you know in terms of staff, the care staff there, right rotating in and out things always are changing in setting who there who is providing service.

If someone isn't aware of this rule or new to it they may not get a whole lot of training or have a very deep understanding what this actually means and looks like in practice at the particular setting.

Where there a lot of changes or staff or administration.

It just something that is going to have to, one more thing to add to our to do list to make sure that this is something we

monitor as advocates at SILCs and CILs in our state in tandem with very partners we've all talked about here today.

I really love that Kathy brought up and hit on exactly first point under the SILC what are things you can do to pull in your entire independent living network.

That put to a goal or objective in your up coming new SPILs. Something around the affect of you've goal to expand and enhance HCBS in your state.

And some of that can look like getting engaged in individual and systems advocacy and all kind of various activities that CIL for that particular objective under that, maybe expansion enhancement goal in your state.

Just some ways to think about doing this that really puts something down and in a plan specific to ill that says we're committed to this and leverage this rule in this way and stay engaged as many levees as we possibly can across the independent lying network as vendors and as SILCs.

So then ongoing cultivation state partnership and collaborations.

I cannot stress this next one enough.

Which building strong relationship and connection to reel relevant state agency leadership.

Something I worked very hard diligently on when I was in Indiana as being SILC director was sending an significant amount of time really building relationships with the leaders

in various agencies specifically that provide a lot of services or have oversight of those programs and services for our peers and facilities and those in the aging community. And mental health community.

And it's been wonderful because I get tagged or taps from those leaders to be pulled into various types of systems change related opportunities.

But also, it what has been really nice if their an issue consumers coming to us about or some challenges that are going on in our state that have been brought to my attention or our attention a SILC.

I can pick up phone or text one the leaders and get that issue addressed or nipped in bud or get my answer addressed if I need it had on the spot or within 24 hours or less.

So again, I, you know, reach out to other state leaders in various agency within your state or ask your D S E to make those connection and leverage that relationship if you have really good strong relationship with your DSE and ask them to sort of help build those ties.

So and again, engage on.

Don't know they will be future opportunity for that, if there is keep that in mind something in another way to get engaged then also, SILCs you know can do state wide awareness education and training events.

How about doing something virtually that for your consumers

you can do this in tandem and partnership with all of your centers.

Let's do a training and virtual training on what everybody rights and protections per this rule.

Let's get them engaged.

Let's pull them into mixing and fold so they become more stronger more empower advocates, right?

Who knows I mean I think we've all probably witnessed an experience where getting folks in our consumers involved in that way would benefit, that yields such a substantial benefit beyond you know issues that we are trying to tackle just in that effort.

Kimberly do you want handle CIL

>> Yes, I do want to say something.

This opportunity is coming to IL to also be involved.

This is often an opportunity that we're often left out of.

So we do need to make sure we're jumping in and really showing the power of our services.

But showing power of our advocacy and voices as consumer led organization.

We should be involved.

We should not be ignored in these conversations.

And so just centers for independent living is a great opportunity to bring your consumers in and bring just people in your state involve them in discussions around this and have

them do something about this.

Our staff was very uplifting for our consumers to advocate for what they actually with went their voice is often not heard.

That great opportunity tore grassroots advocacy but also systems advocacy to bring the community together.

I don't think a lot of even the providers realized the intensity of the final rule.

So bringing us altogether and educating each other is really powerful.

Cultivation of community partnerships we do everything with our DD council we were at the table representing IL and consumers driven services.

So really important to work on those partnerships so you can be a really good team in your state to move forward.

Just engaging opportunities for public comment.

I will say public comment are often not accessible.

So how can you your organization host a public comment time where you can make this accessible and gather information and input.

And send it over to your state Medicaid or CMS.

So really making sure you're working with your Medicaid agency to make sure.

You have even gone to ACL's public comment it is really complicated.

And so we all have to do a better job with making sure

information is getting out there that is fully accessible.
And then just community wide awareness, education, training events.

Again this could be virtual or in person.

Let's educate and give or consumers power to know what should not going on.

Engage youth.

Youth are very powerful as well as organizations that serve thousands of youth per year I will say have youth speak up and using their voice really makes people listen.

I mean that is exactly how we got sub minimum wage will ending sub minimum wage in our state is youth.

People need hear from consumers we do not always need to hear from providers and families.

We need to hear from consumers.

>> I know we're a little bit past time.

If you do have a further question I say encourage you to reach out to NASILC and APRIL.

We continue to connect you to people that have been doing this work in CILs or SILCs or anybody we are wore being with that are other national partners as well to help kind of process how do you get en Gaged in this or what does that look like for you or troubleshooting or if you want to help.

Everybody get into this work.

It's very valuable.

Hopefully this was helpful.

And we will be having more conversations on this.

Definitely be looking out NASILC and APRIL to continuous sent out when site visits are happening when prep calls are coming, when scrutiny calls are happening in your state and when reports are coming out.

We will give you that link and also be forwarding that out to your state when they come through.

Any last thoughts?

All right.

Thank you all for joining us.

And I hope you value a great afternoon and we will be sending a recording and the slides out after this call.

So thank you.