

Scary or Not Scary: Understanding HCBS Settings Rules

October 31, 2022

>> Hello everybody.

We're going to wait one minute until everybody gets on and we will get started in just a minute.

>> Okay.

We will go ahead and get started.

There are a few more people jumping in.

Hello, everyone.

I'm Sierra Royster. I'm the Director of Innovation at APRIL, which is Association of Programs For Rural Independent Living.

Thank you for joining us for this webinar,

Scary or not scary, considering it is Halloween, understanding the HCBS settings rule.

So a couple of housekeeping things before we get started.

We do have a webinar platform today.

So when you scroll over that menu bar depending on what device you are on that bar can be at the top or bottom of your screen.

That's where you will find the closed captioning for today's session.

You can view captioning by selecting the CC tab on that tool bar.

You also have a sign language interpreter that can be found just directly on screen.

If you'd like to change the size of the screen once the slides are shown you can do that by selecting the line in the middle

of the screen.

that will slide to the right or left to make the slides or the interpreter larger or smaller.

If you have any technical issues please use the chat feature for that today.

You can use the word bubble and same menu bar.

If you would like to turn the chat feature off if you are using a screen reader you can do that by pressing Alt H or please use the help section on the APRIL website for more information if you need it.

I will also drop my email into that chat as well if you would like to contact me in the chat with a technical issue.

We will have a question and answer time at the end of today.

Please note the question and answer box is on the menu bar.

And so if you have something that you want to make sure gets asked in there, go ahead and drop that throughout the time and we will review those at the end.

We will have -- during that same question and answer time you will have option to raise hands.

And so I can unmute you at that point.

And then you can press star 9 or Alt Y on your keypad to raise hand and then star 6 to unmute or Alt A using key strokes.

Once you join keep the conversation background noise down so we can hear you as clearly as possible.

Okay. So thank you.

That's all the housekeeping items, but please let me know if you need anything throughout.

I am going to go ahead and start the screen sharing so you can see our slides for today.

Okay.

So first off we have several of us talking today.

We thank you for joining us.

I'm again Sierra Royster. And we will have Katy Brady and Amber O'Haver, Jay Harner and Erica McFadden.

So thank you so much for all of them for joining as well.

A couple of objectives we hope you leave with today; who are the stakeholders and important partners in your area.

So start to understand the role of the HCBS settings rule.

In case you do not understand that we hope you leave with a little bit better understanding of that today.

Then how does this apply to your work?

How does this apply to your center or CIL?

and what can you do with it after?

And where do you find information on this rule?

So there probably will be lots you still need to learn if this is new for you.

We hope to give you some places that you can go that you can access some of this information.

And then once you have this information, what do you do next to promote those rules and find information about it?

We hope that will be a little bit of what you will come away with today.

Also you'll have to forgive me, I'm having a bit of a cough this weekend.

and it only likes -- it only makes me cough when I have to talk.

So this is fun.

But, how did APRIL get involved with this?

This is a partnership that NASILC has been working with HSIR on.

And this is something that we are hoping that we can encourage the work that centers and SILCKs have been doing in

independent living and transition work for a very long time.

But to understand there's a setting rule that has been in place for a while but some of that work and how that looks in your state may look very different.

But that also can enforce kind of what we have been saying as community choice for so long and then consumer control as well within that choice.

So some of these rules are kind of reinforced with what we've trying to do and independent living for a very long time.

So just seems natural to give those resources and help get you connected with those partners in the community.

Some of our role we will bring awareness to the membership and IL partners on this role.

This one way we're doing this is today.

We'll have couple different things we will be doing with this work.

But in order to know about it you have to be aware of it.

A lot centers probably are not aware how this rule As them.

We hope through these situations, excuse me, you will be able to do that.

Okay.

>> Kate, I'm going to ask you to go ahead

>> I'm happy to do that, I'm so sorry you are with us while you have a cough.

His the season.

Go back a slide and I'm happy to cover -- yeah.

So my name is Kate Brady.

I'm a project manager at the human service research institute.

And we host the national center on advancing person centered practices and systems.

And it's through that center that the administration of disabilities and administration from community living is funding this home and community-based services partnership that we're so thrilled APRIL and NASILC are a part of.

So APRIL's role since Sierra able to get through, APRIL's role is to bring awareness to your membership.

To independent living partners on the HCBS settings rule.

Which couldn't I couldn't agree more.

Aligns completely with IL philosophy.

So we're hoping that we can equip CILs and SILCKs with the information will allow auto increase your efficacy around transition and diversion from institutional settings where we can provide you with resources so that the you'll better able to educate the people that you're interfacing with in the community.

And that we can identify those of you that are already doing this work and position you as within the network.

So that is kind of the aims of the partnership.

Next slide.

Okay.

So quick visual description.

Kathy I'm comically in my witch I committed to my children I would dress up this year I use home and community-based services to get ready for my day.

You just have one opportunity to get ready.

So it was an all or nothing proposition.

So I'm here with you in my costume.

Comical as that is.

And I guess other thank you for the support and the chat there.

Other visual descriptions middle aged white woman with short brown curly hair.

And my background is a kind of blue green human service

research institute background.

Next slide, please.

And just to plug there's an interpreter who needs will need access to using her camera online.

Just a plug for, Sierra, so that she can promoted to a panelist.

Her name is Amanda.

All right.

So the who and what of home and community-based services or HCBS.

What are home and community-based services?

These are the services that are funded to support things like supported employment, finding a job, keeping a job, getting accommodations on that job, transportation, very often people are using Medicaid waivers for activities of daily living support such as bathing, dressing, toileting, cooking.

Perhaps like housekeeping, in-home services like PT, OT, speech therapy, medications finances as well as assistive tech in home modification.

So you can see that home and community-based services are really underpinning our access to really critical daily supports for live an independent life.

In 2018 more than 4.7 million people received these Medicaid funded services.

And each state its own system for administering Medicaid

waiver HCBS.

They decide which populations they will offer these waivers to.

So the home and community-based settings rule is a federal rule, there's tremendous variation in the states which is why your expertise and knowledge advocacy or going to be so important.

Because we have to be working on the ground locally in states to advance these changes.

Next slide.

Thank you.

So a little background.

Where did this role come from?

Why are we doing this?

Well we knew that people are living in community-based settings still living in a life that was closer to an institutional experience be that in group homes, so in 2014 the home and community-based final rule was the very first attempt to really define when we say community-based, what do we mean?

What meets that has threshold?

Since 27th 14 we have been in what we call a transition period.

In March 17th of 2023, that will be the end of the home and community-based services transition period.

Meaning that those services that don't align with the requirement have to come into compliance.

So the time is now for advocacy.

We will talk a little bit more about particular opportunities for advocacy.

So thankful ACL and CMS are being very steadfast in ensuring that our services adhere to tenants of the rule regulatory criteria.

Though these provide the framework for ensuring that services are to be person-centered.

And that settings within which those services are provided facilitate autonomy.

And independence.

You can see another alignment the with IL facility.

Next slide, please.

Thank you.

So what does this rule require of service and supports?

It requires they are integrated and support full access to the greater community.

It requires that the person receives services in the community with the same degree of access as people not receiving federal Medicaid funding.

So that's the box.

Any person not receiving services that level of access should not be different or diminished by fact they are receiving

services.

And it requires that service and supports provide opportunities to seek employment, working competitive integrated settings, engage in community life and control your own resources.

Next slide, please.

So what exactly makes a setting home and community-based?

It is in the community.

It should provide that full access.

As we said, it should provide opportunities to seek employment in an integrated settings at competitive wages,

Allow participation in community life and control resources.

It should also always be selected by the person from options that include non-disability specific settings.

So really important.

So in menu of options there should always be options of non-disability specific setting.

The rule ensures right to privacy and freedom of respect and freedom of coercion and restraint and facilitates individual initiative autonomy and independence in making life choices.

So that's a very specific requirement, right is this so when we evaluate these services and when you're in conversations with people about their life and the supports that they are receiving, you can be listening for violations of people's freedoms or situations in which they've been coerced or maybe

their independence in making choices has not be upheld.

Those indicate violations of HCBS settings.

Next slide, please.

All right.

The requirements at the state level are that the state has to ensure that all of the services meet the minimum services standards integration access to community life, choice autonomy and other protections.

It also require that is every person's service are driven by person-centered plan.

They have to receive final stayed-wide approval.

So we will look at which states have already submitted their transition plan and had it approved and which states have yet to accomplish that and you can get involved.

Next slide, please.

So thankfully there are some additional requirements when the setting of the services is provider owned or controlled.

And those are requirements are here.

The unit has to be owned or rented occupied under a legally enforceable agreement.

It has to it allow for privacy meetings people can lock their bed courtroom doors.

People have to have choice roommates and freedom to deck rate the space as they choose.

One should have control over one's own schedule.

So that means not only what services one gets, but when they have them.

Right?

Access to food at any time.

So that means unless there's something in the person-centered plan that says I really want to change the way I eat, I really want to make sure I don't eat after 11 at night, there should be no limitations on access to food.

And any person living in a provider-owned or controlled setting should have choice, should have access to visitors at any time.

Next slide, please.

All right.

I put it in here twice.

Because it is that important.

And you would think that these are kind of basic rights that we would assume that any adult living on their own would have, right and we shouldn't have to stipulate.

But unfortunately, we know that there are many -- people all over the country that have disabilities of various kinds where Medicaid is funding services and they do not have access to food or they are told we can only have visitors on Saturday afternoon.

So it's really important that we have these things in mind.

Control of schedule and activities.

Of course physical accessibility.

And key to note here that as I mentioned, any deviation these has to be supported by a specifically assessed need in the person dash centered plan or individualized service plan.

When a plan to reevaluate and return those freedoms, right.

So not indefinitely that I can't eat my cheese puffs after 11 p.m.

It is once I have accomplish ad change in my habits or once I've accomplished the change in my weight and what supports am I going to receive to regain access so that I have autonomy to make decisions.

Next slide, please.

All right.

So this person-centered plan that drives all services has some requirements thankfully in the HCBS settings law.

That us it should always identify strengths, preferences, needs, both clinical and support needs.

And any desired outcomes that the individual has.

It should include very individually identified goals and preferences.

And these goals and preferences should speak to relationships, community participation, employment, income, savings, healthcare and wellness, education, anything else that is both important to and important for the person.

And it should reflect what is important to the individual and

speaking to the manner they want services delivered so that that is ensured.

It may identify any risk factors so that supports can engage to minimize those.

And the plan should be understood by the individual, that means it should be free of jargon and they should have a primary voice in the development of that plan.

And of course it should reflect any cultural considerations.

Next slide, please.

All right.

So why are we talking to you about this?

Why are we so concerned about public engagement?

Well the administration and community living works closely with CMS to implement the settings rule.

The rule is key to engaging community members in the development provision and the oversight of HCBS programs.

We're so grateful that for the very first time ACL specifically is funding public engagement efforts.

So next slide, please.

So what do we mean by public engagement?

Is well there are a number of opportunities to engage and a number of methods that you can take.

And we'll go over some of those.

In short-term I will put link in this chat after I'm done going through the slides, every state has a state-wide

transition plan.

Meaning what are their plans for ensuring all the places that deliver services are in compliance?

And they have to release that rule for public comment, consider those comments, revise it and finalize it.

So there are opportunities during that process for people with disabilities, their families or the organizations to look at that plan, see what they think and provide comments.

There's also heightened scrutiny package.

Heightened scrutiny very simply means that a state agency has identified as not likely in compliance now.

And states have to make plans for how they expect additional federal oversight to review those sites and how they will in the future come into compliance.

So they produce what's called a height scrutiny package.

CMS, centers for Medicaid, will identify some states around the country each year to do site visits.

They go and look at those sites so that they can provide monitoring and feedback about the experiences of the people in those services.

And they are always, to opportunities to engage.

There are also corrective action plans.

So CMS put forth the opportunity for states to show that their policy and procedures reflected setting criteria that they are making attempts to implement the criteria to fullest extent

possible.

But that they are going to make corrective action plans to allow for more time and more actions to bring those systems into full compliance.

And then I put in bold here waiver amendments and renewals. Because when we are all said and done with the transition period all states still deliver home and community-based services through waivers, Medicaid waivers.

And you are probably serving tons of folks who come into CILs and probably SILCK and about their experience on waiting list. It is waiver document and any times in which state proposes amendments that there are always opportunities for advocates to engage.

So that really important one to keep an eye on.

Next slide, please.

So here's just the restate, I think we've covered those opportunities for engagement.

Next slide, please.

So when we say stakeholders who do we mean?

We really mean everyone.

We mean individual people with disabilities and their families, advocacy groups, every kind of advocacy group.

Self advocacy groups.

Parent groups.

Sibling groups.

We also mean the P&A protecting and advocacy organization in your state, ombudsman office.

Adult protective services.

Today most importantly Centers For Independent Living and State Wide Independent Living Councils.

Next slide, please.

So as I mentioned there are a myriad of ways that you can get involved.

When a state posts a period of comment you can show up in person and give a public comment.

That can just comments on your experience or something in particular you're concerned about regarding the state system.

You can submit those same comments in writing.

You can also coordinate templates for others to use in submitting their comments to support people and knowing what to say.

You can consult a partners in your state.

ACL is currently funding the national network.

So not only at APRIL and NASILC are involved in this work but the national association of DD councils, the national disability rights network and ACB, the association for university centers on disability as well as ASAN are all involved.

So any given state you probably have partners that you can working with to submit comments.

Always you have the opportunity to call your elected officials.

And I think for your day-to-day work, the opportunity that we really want to support you in is to help someone who receiving services be aware of their rights and be able to decipher when those rights have been violated and how that applies to the home and community-based settings rule.

Next slide.

So quick review.

Settings ought to be integrated.

They have to ensure right to a privacy and respect autonomy and a freedom from coercion and restraint.

And provider settings have additional requirements.

And all services should facilitate choice.

Next slide.

So when we're thinking about the state system I want you to be aware of these deadlines.

March 17th, 2023, that's the deadline for state compliance.

You can look at this link here and that's how you'll know whether your state has already attained final approval.

KAPS or corrective action plans are do you January 1st, 2023.

States are not required to release their corrective action plans for public comment that does not mean you cannot call and say we would like to understand if you're thinking about submitting a corrective action plan.

We would like to have a chance to talk through that with you.

You can always make those requests.

And then we anticipate continued CMS heightened scrutiny reviews for any settings that are considered presumptively eligible.

And we have seen, it's really important for you all to know, we have seen already when advocates identify sites that are of concern to them and communicate that those sites go on the heightened scrutiny list.

It really does matter.

And all of this stuff is super complex.

And the most successful states are working in coalition with other organizations.

Next slide, please.

All right.

I think we covered this.

I'm going to keep going in interest of time.

Thank you.

All right.

So yeah we should skip this one too.

Yeah.

All right.

So by January 1st states have to have told CMS what is their oversight system, licensure, certification, prior manuals, person-centered plan monitor thing.

They also have to tell them what assessment process that they will be using for initial compliance and ongoing compliance of settings.

And they have to describe what is the beneficiaries, resource what is your option if you notice a provider is not in compliance.

They will call this grievance process.

Might be notification of the case manager.

It will be different in every state.

So it's very critical for when you know what the grievance process of beneficiary recourse is in your state.

And the state has to say how they are going to respond.

Right?

So not a one way, it should be closely watched.

Next slide, please.

All right.

Here's a map that I won't go over because you can access it on the link that we will put in chat, but it just shows you states that have pending state wide transition plans and initial approval or final approval.

Next slide, please.

All right.

As a reminder, corrective action plans can include, this is important, they can include modifications to the state's compliance plan ensuring all services provide access to the

broader community, opportunities for employment, private unit and/or choice of roommate and choice of non-disability specific settings.

In other words a corrective action plan may delineate how a certain part of the home and community-based service system in the state is not yet compliant with those requirements.

They have to be concrete and time limited.

And they have to, they have to address how the state will in the future ensure that access, opportunities for employment choice of private unit or roommates and choice of non-disability disability settings will in the future be made available.

Next slide.

So they have to be able to show that they have a plan and that they have done everything they can to adhere to these requirements and they are not falling short and their plans is how they will get there.

They are encouraged to seek public input.

So I'm encouraging you to initiate that conversation with your agency.

Next slide, please.

And then there we are.

We'll go to the State Wide Independent Living Council.

I'm thrilled to pass it over to Amber.

Executive director of NASILC.

>> This is Amber speaking.

Thank you, Kate, I appreciate that.

A lot of really, really great information.

I even learned several things that were new to me too.

I appreciate that.

So good afternoon everybody my name Amber O'Haver.

I'm vice chair of NASILC and current executive director of the Indiana State-Wide Independent Living Council.

I will address the intimidating or scary related components of the rule and how the SILCK play a role or can play a role in advocating to ensure compliance in our peers' rights when it comes to HCBS setting role.

Let me give a visual description.

A middle age wide woman.

Very long blond hair pulled back with black head band.

I'm black and white V neck sweaters.

I have silver little ball earrings and silver necklace on.

My background is blurred but I'm at home in my office today.

And again, happy to be here with everyone.

Go to the next slide, please, that would be great.

So before I dig into start going through this I want to say

I'm really thrilled to be working with various national partners.

And I so appreciate APL really providing NASILC and APRIL and MDRN and all the other national groups the opportunity to

receive some funding to do work in some space.

Particularly NASILC because it just the HCBS setting rule really presents a great opportunities for SILCKs to really dig into their duties and exercise their authority.

Which again I think is exceptional and this thing that quite frankly the independent living network across the country and our state has not had the opportunity to do a lot of work around when it comes to specifically identifying advocacy opportunities when it comes to HCBS settings rule.

So here we are.

So I want to start with just identifying talking a little bit about building and bridging partnerships or collaborations in your state a SILCK.

And the role of the SILCK when it comes to it.

So what I'm talking about building and bridging partnerships and collaborations, the importance of those is essentially how can you come together with those various agencies entities, consumer directed groups in your state and work together or leverage your different strengths and knowledge, right to advocate to ensure the rights of disabilities when it comes to the HCBS settings rule.

So when I'm talking about state agencies I'm essentially talking about entities that have oversight sort of control overseeing development and implementation and compliance when it comes to the state transition plans.

And then when I'm talking about state advocacy entities I'm really talking about all various advocacy in your state like protection advocacy system.

The DD council, even ACLU state chapter.

AARP state chapters, ombudsman.

when it comes to long-term care, the list goes on and on and on.

Essentially anyone that fingers or you know, advocacy efforts engagement when it comes to home and community-based services or just community living in general.

So it another role or another piece of the work that SILCK can get engaged in and that really can play I think a very strong role when it comes to the HCBS settings rule is around information dissemination and educational awareness.

So what I mean by this is the SILCK can arrange and schedule and set up some training to educate the CILs and their consumers or board members about HCBS settings rule to better understand what that looks like what it is and what the purpose is, and how it is directly tied to independent living philosophy, which is great.

And then also disseminating information and doing some educational awareness efforts and activities when it comes to consumers and peers with disabilities.

So one of the ways I think that really gets back to why it important to have strong partnerships and collaborations in

your state with various partners is because when it comes to information dissemination and an educational awareness it really important to tap those partners to help you disseminate the information.

So for example, you know your P&As are ones that access in terms monitoring visits to lot of spaces and places and facilities where our peers are.

And very easily share and provide information about the rule and what their rights are in language and ways that is easy to wrap their heads around and understand.

That is something you can work with partner on to develop.

One really great resources I would say again and express to everyone here is ASAN is phenomenal.

They have phenomenal resources in plain language and lots of other templates and lots of other toolkits that are really great and really helpful and can also be tapped and tweaked to your needs or your state to share and disseminate and push out through those various partners you have.

Your AAA is another great one to also tap to help you disseminate information about the settings rule.

So I would also advise developing partnership and collaborations with them to sort of link up together and start working together ensure rights of people with disabilities in your state when it comes to the HCBS settings rule.

Next slide, please.

So this really gets more into the systems advocacy piece which is really an example of how a SILCK can dig into its authorities.

So systems advocacy when I'm talking about that when I'm talking about a settings rule what is already happening in your state when it comes to systemic activities that you can engage in?

Recreating wheel or starting something over again or something that is already occurring can you get in work groups that are already taking place?

Can you get involved in tag teaming on training opportunities to educate our peer with disabilities and what their rights are when it comes to the rule.

What is already taking place?

What is happening in your state really to dig into.

And if there isn't a lot happening in your state or anything or there aren't opportunities necessarily that you think are a good fit for the SILCK at that time you could also then as a SILCK really start to develop or implement or create and lead and direct your own advocacy opportunities and pull those partners I talked about a minute ago into fold in work you're doing a SILCK.

The so SILCK can engage through work that already occurring and become a part of that work.

It also can lead and direct some varus out type advocacy

opportunities to help ensure compliance with the rule.

And then also, again, to ensure the rights of our peers with disabilities.

The next thing is around can you remember engagement.

This piece I think is really important.

When we talk about the SILCK there isn't always necessarily a lot of thought around consumer engagement to be quite honest or Centers For Independent Living ones that do a really great job providing direct services and day-to-day services and engaged with consumers on the ground every day doing work around diversion transition and home and community-based services related advocacy supports.

So I would say the for the SILCK one of the ways you can help address this advocacy needs when it comes to the rule is really looking how having a SILCK helped recruit and bring in people into about fold doing this work learning about it, gaining knowledge which then helps to empower them which next one I have on our slide.

For example Indiana one. Ways we have done that work a SILCK really utilizing our existing leadership programs.

So a lot of SILCKs across the country are hosting youth leadership forums or youth leadership programs.

We just did another one this past summer, a virtual all virtual event or programming that was shifting the narrative.

And built in a lot, a lot of this type of education and

training and awareness when it came to rule and other HCBS-type issues that are experienced here in Indiana. But not only talked about them and educated them on the issues, work together as a peer-to-peer network and group to really get into the space of brainstorming around action.

Like what do activities look like?

What do next steps look like in terms of consumers do we work together?

Do we work with SILCK and other partners to bring them in. Really just about thinking more broadly in terms of consumer engagement when it comes to recruitment and empowerment and utilizing what you're already doing a SILCK if you're doing any of those type of programming.

Other thing I would say when it comes to consumer engagement, I think is honestly we as SILCKs don't do enough of because we're so engaged, engulfed in doing the work sometimes we forget, it's a privilege to be in spaces where there is some pretty heavy gatekeeping that often happens for us as people with disabilities.

And so we have this unsaid responsibility quite frankly to leverage that privilege in that space and who is not here at the table that my peer that needs to be here.

Who else can I help get here in this space to learn about the advocacy or the information that is being shared when it comes to the HCBS settings rule or are there advocacy efforts taking

place that our peers with disabilities can engaged in and then how can we as SILCK make sure we get them pulled into the fold and working together and collaborating with the existing group to conduct those advocacy opportunities.

Next slide, please.

So this is sort of where I -- when we were forming and putting this presentation together we talked a lot about you know, what can a SILCK currently do where should SILCK currently focus energy and time and following this our final slide which I'll talking about in future opportunities and ways SILCK can focus energy and time when it comes to advocacy efforts around the HCBS settings rule.

So I would first say one of the things really important for SILCKs to do is find out if your state has final approved state transition plan.

If it doesn't, find out why.

I think if you're wanting to know how to navigate that and Kate touched on this a little bit but you can ask your DSE will know actually where to point you to get access to the state transition plan.

Or if you have a relationship with other state leaderships or agency folks you can also tap them and ask them about and request a copy of the state plan.

So in Indiana, for example, one of the things that we are going to working with our state on to ensure greater access to

the plan.

And Indiana's plan was approved in June they didn't push out that information until September.

When they pushed out that information they pushed own announcement if you would like a copy plan you need to email us to request it.

Okay.

So I did that.

Well wouldn't much easier and much less restrictive if we could just click on a link and up would pop the plan and we would access to it right there instead of having to ask for permission to get access to copy of plan?

Those little things are ways we can talk with our state agency folks to ensure greater access to information we need to be their advocate to do this work.

So the other thing I would encourage you to do is review the plan.

I will say, Indiana's plan 167 pages long.

These plans are not easy to read.

They are not necessarily easy to follow.

And they are extremely long.

So one of the ways that I think you could also leverage or tap some of those partnerships that you have with other entities in your state is to contact your P&A or DD council or youth center, who every you're working with or you know and are a

relationship with in your when it comes to disability related advocacy or services and say hey, do you know much about this plan.

And if you do, do you have anyway you can help me break this down and understand this?

Or I have these questions, can you walk me through this.

I know in Indiana that is something I do a lot with our P&A because they tend to have a much deeper level of knowledge and experience when it comes to these plans.

Because they've been involved in from most of them from the beginning in their state around provide around written comment and being involved in development work groups when it comes to work plan and all of that.

So they have a little bit of a deeper insight a lot of times and better equipped sometimes to answering questions you may have about the plan.

So they are a great resource.

Your partners utilize them.

Leverage them, don't be afraid to reach out even to your state agency folks.

We have an excellent relationship with our Indiana Medicaid director here.

And I tap her for information questions all the time.

Which she appreciates because some goods are not on her radar.

Some things she's not aware of.

And when I reach out and ask questions or pose inquiries to her, it helps raise her awareness of things they need to get better in doing, right?

In the state agency where these kind of issues are occurring or these plans exist.

And need to be implemented appropriately.

So also Kate touched on this, but, how essentially is your state planning to provide a grievance process?

What is that?

What does that look like?

Is it clear?

Is it transparent is this is it something you thing you and your peers our peers would able to easily navigate?

Think about that from a lot of different types of disabilities when you're considering that.

Some other questions are around how does your state plan or transition plan depress need of consumer transition.

So if there's a site that says you know what, we're not going to get to be in compliance have to transition folks out of here we can't continue to serve them.

Oh crap, what happens then?

How is that being addressed in plan?

Do you think it appropriate or not?

You know, dig into that and look for that kind of information.

The other key piece I think often gets missed is how is your

state transition plan addressing issues of equity?

How are they addressing specific needs or prioritizing folks who are multiply marginalized and are people of color who with disabilities who are individuals who are part of other marginalized groups and communities.

So I know it may seem kind of Audrey to think well we're talking about home and community-based service what to ensure equity.

I will tell you a lot.

So, I would not be surprised if there isn't much when it comes to addressing these kinds of issues of equity in these plans. So it's an opportunity for you to dig into that with your state if that is something that you think is important which I think it is.

So next slide, please.

This one I won't go into de-A. Lot detail but one ways to dig into and find out your state is doing weaving, webbing a lot of these advocacy efforts or implementation or state wide transition plan when come it is to the settings rule is looking at other plans of your state.

Do we this our state have anything in a setting rule?

If we don't, why not?

Let's dig into that.

Same thing with DD council five-year strategic plan wee state plan through voc rehab.

State P&As are required to do priorities and objectives on regular basis.

How is the HCBS setting rule being addressed through priorities and objectives of your P&A.

In Indiana we're develop a state plan on aging you bet your butt I'm going make sure as a SILCK there are issues addressed in there when it comes to the HCBS settings rule.

And are there other plans in your state that maybe aren't federal related plans you need to have but are really important and key to addressing this from a more comprehensive level when it comes to compliance with the rule.

Next slide, please.

This will be my last slide.

I will turn it over to Kathy to facilitate our panel.

But what is the future for SILCK involvement or sick focus look like?

What can it look like?

I know right now our SILCKs are looking at amending our current plan to do 1-year extension.

Is it a possibility that you might want to build into that some education and awareness training and activities or efforts as a SILCK to address this HCBS settings rule?

So think about that.

Another thing to do you do decide to do that, you could then get everyone prepared in your network be educated and up to

speed on the rule and then be able to build out and dig into the rule a little bit more in the development of the CIL and use it a really great, the CIL is a really great tool or mechanism to address advocacy related efforts and issues when it comes to a rule from IL network perspective.

Not just the SILCK, not just the CIL.

It really all encompassing.

A lot of SILCKs have states on state commission on rehabilitation.

How can you leverage that is this how can you ensure that you as a SILCK in that seat, whoever that might be, SILCK staff, SILCK member, how are you asking questions about the rule and how that commission is addressing compliance with that.

So other thing is I mentioned partnering with different various groups in your state to conduct education and straining events for peers with disabilities on their rights and in accordance with the rule.

I think it would be useful to tag team P&A.

And doing some train thing for folks in these settings.

And then also, you know talking to more doing, talking to them about doing, you know, what is the rule?

What is the purpose?

Why is it needed?

How does it apply to me as consumer and my peers with disabilities?

And then, provide some examples of what violation of that rule would look like for folks.

And then talk to them about, what do I do if my rights are violated?

Who do I contact?

Who do I notify?

How does this work?

Has how does this happen?

And again, hopefully, you've working and engaging with your state on allowing or providing for very clear and transparent grievance complaint process.

Again the last thing, what does engagement of consumers or people with disabilities look like when it comes to ensure compliance with the rule?

Site visits a really great one.

In tandem with CMS, op they pull advocates in to help.

That's good one.

Another one is pushing out advocacy alerts.

We do that lot here.

Our peer latch on to those and we provide action alerts.

Not just the opportunity, but templates and actions that folks can take to help make it a little bit easier for our peers to engage and continuing leverage like leadership programming and training you do as SILCK.

And we host a lot of times these disability community

conversations that are just spaces for people with disabilities, no one else.

We talk about services and then typically we end those and wrap those up with some calls to action and what that looks like.

That is a group developed and decided decision.

Just really reinforces consumer direction and the peer to peer support model of independent living is beautiful in providing to our disability community.

With that I will end and wrap things up and Kathy, I think you're up.

>> Hello everybody this is Kathy Cooper I'm going to step in and help Sierra of verbal description of myself I am a white woman in my early 50s.

I have brown-blond hair. It is pulled up in a messy bun on my head with a pink and mauve shirt.

The background is a white wall with a red white and blue picture.

I am the chair of the National Association of State-Wide Independent Living Councils.

And I'm also the executive director of the SILCK in Kansas.

I'm going to have a few questions for our panelists.

And we're going to have Jay Harner and Jodie from a roads to freedom Independent Living Center join us along with Amber OHaver you just heard from.

We're going to ask them some questions about the work they are doing in this area and how it strengthened advocacy in this work.

Kate will help me with this too.

So we will get started.

I'll go ahead and turn on my screen so you can see panelists and interpreters a little better.

What are some activities that your CIL and SILCK is doing now around HCBS and what is worked for you to get stakeholders engaged?

Feel free to jump in Jodie, Jay or Amber.

>> This Amber.

I can jump in.

One of the things I know we do, so we are involved pretty heavily, we do a lot of work around that.

Obviously the HCBS piece doing, you know, ensuring community living and access to community supports.

We do a lot of work around that in Indiana.

our self direction planning is like bottom of the pack in terms of entire country.

So there's a lot work that needs to be done.

The other thing we do our SILCK hosts conducts a monthly long-term advocate coalition meeting.

that coalition meeting is essentially consists of a majority 80, 85 percent of people with disabilities.

And they essentially determine and figure out how to get involved in when can comes around community can integration and HCBS.

It doesn't hurt to compensate our peers when you have ability to do that for their time and experience and because their lived experience our lived experience is just valuable as professional experience that folks have that we work with on a day-to-day basis.

>> Hi this is Jay.

One thing we do we work on advocating on consumers' behalf. We get lots of calls on a regular basis for individuals looking for and unaware of what services are out there for them, how they qualify, what the financial restrictions are. And we've been advocating throughout the state to expand services and working with our state budget to expand pay and add again fits overtime.

They have experience since COVID, unable to find direct care workers because of rate of pay has not gone up substantially in comparison to many of the different sectors of employment that is possible within our area.

We are in center part of state which a little bit more rural. We have issues with transportation not only for consumers but for direct care workers.

So getting people to get to their homes to remain independent the in community and safe has challenge right now.

We're working on the state to expand that.

We did receive an 8 percent budget increase several months ago.

But inflation and price of gas it hasn't really touch ad lot of things for some.

I take a lot of calls just how the process can started.

What they need to do.

Everybody else myself I'm quadriplegic I'm paralyzed from neck down.

I broke my neck when I was 18 years old.

I've used HCBS since January '98 not only do I live it but my profession I promote it.

And advocate to remove barriers for anyone that wants to live independently on their own and stay out nursing homes which are like prisons.

Once people are subjected to go into facilities, we will get them out.

Anything we can do to keep them it thriving in their own personal comfortable environment what is we do on a daily basis.

>> Okay.

Thank you guys.

We will go on told next question.

>> How do you see advocating for this rule as being important to IL?

And how do you think we can spread the message of its importance?

>> This is Jay again.

IL without these services I would in nursing home.

Many other individuals need, you know, as we learn about the services I need assistance with showering bathing and getting dressed and food preparation, temperatures.

All of the things that you know daily activities that allow me to remain independent.

So for us to promote those services for individuals that are out there that there know this, I get calls everyday again people I heard about this transition program or what is independent living?

What can I do?

For somebody that is you know adult child living with their parents and 35 years old doesn't know what to do as they get older and never heard of independent living because all they've told is live on their own do anything.

And they become almost, you know, recluses in their own home because they this know what is available out there.

The more we know and remind people what is available, better off we will be as a whole.

Jodie, this is Amber.

I don't want to take from you

>> I with us

>> JESSICA: Going to support Jay.

Continuing advocate for supports and services that are already out there.

We always say that specifically centers for independent living sometimes are the best kept secret.

Oftentimes people this know what we do or you know, what services and supports it that we can connect individuals to.

So education is always at the front of our game plan, you know, how are we going to continue to push it out?

Is I can say that you know, at our center, one of the things that we use the most is social media.

There are so many different forums of social media out there and opportunity to educate others by doing so.

>> I'll follow up on that.

Again, she said we are a secret.

We tend to be especially in our area.

We will get our name is center for independent living.

People will call and all the time ask if we have any rooms available because they, they hear the name and that's first things do you have rooms available kind live there.

So by just promoting being interactive in your community a lot of outreach and try to attend as many events as we can.

We have open door policy here bringing in more groups all the time but show them what we do, we're not just -- we provide employment services.

Peer mentoring, I mean I can go on and on.

And people would call and say I have no idea.

Give me a call just asking for information.

You know I had someone call looking for a lock because we ended up talking about the waiver services how they can get -- because she was paying, she literally paying somebody ten hours a month living in her apartment area to help her go shopping, you know, personal needs.

and she's -- and probably getting one shower a week.

And she is crying to me on the phone that she wants to do more but she can't take care of herself.

So, you know that one call about turned into the program, assistive technology.

She doesn't have cell phone or tablet.

She's by herself.

Here we have a through the university we can assist her with providing free cell phone.

Demos how to use it.

She's eligible for snap benefits which food stamps here in a Pennsylvania.

She's on free phone service.

So a two minute phone call she thought she was going to get no information from turned into 45 minutes of her being overwhelmed with what we can provide and how we can help her.

>> This is Jodie again.

I just want to add that a lot of our work is not only based in our county, but state-wide and federally as well.

We're always looking at all aspects, you know and how can we people with disabilities to table so their voices are heard.

>> Getting to sum up this question.

This rule is an independent living.

I mean, it is a very heart and core of what we do and our philosophy.

The CILs are just phenomenal resource to tap and refer folks to when their rights are being violated.

They don't know what their rights are when it comes to setting rule and making sure we leverage our partners and collaborators to share that information with folks in these types of settings where the rule is applicable.

And ensuring that they have information to access the CIL in their area so they can get access to all of the phenomenal services that Jay and Jodie have just talked and shared today. And then can also ensure that if someone's rights are being violated after they've educated them on what rights are based on the rule they can help them address that and walk through navigate that process.

Because it can extremely intimidating.

A lot of folks are very scared to address and hold folks accountable in these facilities or settings if they are violating the rule.

So tie it back to the rule there.

>> I'll follow-up on one other thing.

Recently in the past, especially since COVID we've come across guardianships.

We've run into many who get locked into a guardianship.

Not even to their knowledge.

And these tend to overtake an individual's life with no rhyme or reason, just because they went into a hospital for a simple a simple, sickness or injury.

Next thing you know they have some complications and before they know it, and a state AAA so we start vigorously working with the state and lawmaker and Congressmen to educate individuals and how guardianships are being used to almost prison these individuals.

I don't want to go too far but they get locked into a guardianship they have no say in their life.

They have nothing, no finances their care where they want to live, how they want to live how to be treated.

They are told really they are in print, when to sleep, what they are going eat, when they are going to eat, how they are going eat and so on.

We've which across that working with the state to educations and try to peel back.

>> All right.

>> Guys, I have to cut it short.

I'm so sorry, Amber.

we are running quite a bit behind.

I do have to go ahead cut this a little bit short.

We do have commissioner Jill Jacobs from the office of independent living programs with us.

And I know she has some things that she would like to say so we will go ahead and cut away to Jill.

Go ahead, Jill.

>> Hi, everyone.

I'm Jill.

I am the commissioner of administration on disabilities.

I'm very happy to be here.

So I want to talk a little bit about the settings rule and why it is so important.

When we talk about settings rule I thought that this is something that the centers for independent living, I was an executive director of CIL.

I wasn't really familiar in my role about what this meant, what does this mean to as Centers For Independent Living?

How does that affect people with disabilities?

And so I want to be clear what settings rule really means.

The settings rule lay things out some very basic rights for people with disabilities.

Things you wouldn't need to I can be laid out.

Things like for people who often live and people who live in

setting like group homes often, people who are living in environment things maybe, you know groups of people living together than their own place in HCBS.

Maybe people who receive day services.

People who live in what is considered an assisted living or Independent Living Center.

But it's really just right here next to nursing home and one other hallway in a nursing home.

But those services are being covered under home and community-based services.

So these are the torts of things that we are looking at, that we are looking at states and providers how are these services being provided?

We're looking a basic, basic civil rights that many of us can't even fathom because we're part of independent living movement, we are IL and we don't even think about reality that there are people out there that live in HCBS settings and they have never experienced these most basic rights.

Okay?

So these are things like I can have a lock on my door.

If I'm hungry I should have access to food when ever I want it.

My food shouldn't locked up.

Nobody should taking my snap card for me and buying food for whole community and using sliding my card.

These are I mean, they are really, I should have an opportunity to choose when I shower and bathe.

You know, who I hang out with if I want a beer on a Friday night.

If I have intimate relationships.

Can someone come over is visit me where I live or are there rules around visiting hours?

Those are really basic things that lot of us in the independent living community have not ever experienced.

We're so used to directing our own care and yes, I know we often feel in IL movement numbered listens to us we don't have our own voice.

And that's true.

But y'all I'm talking about whole other level as they say.

And so that's what we're really working on here.

That's what we're really focused on here.

When we are looking at this we are looking at this key tenant of nothing about us without us.

That's a big part of who we are, right?

In the IL movement.

So when it comes to the HCBS settings rule we are really wanting to make sure to a big push for us not just something I've saying.

I'm going to put funds towards moving this advocacy ball down the road to making sure people know this exists.

You know, in this particular situation, HCBS settings rule it's a requirement that people with disabilities are at the table.

They are being heard their voices are getting heard at the state level that there are, there's a public comment opportunities.

Okay.

But we at ACL know even when is no the a requirement according to some rule it should always be the reality.

So for us the HCBS settings rule I view it at first step in big process around advocacy.

You know we want to make sure that we are participating in the process and making sure that we are informing and engaging and a we're giving people the tools that are needed to really and truly be part of the process.

So we want to see a cadre of knowledge filled advocates engage fully in making that change happen.

And I see HCBS settings rule as a first step in it.

I want to see us being successful.

I want to see us engage in a way that we can see CMS listening to us, that we can see change happening at the state level and at the provider level.

Because we are being heard.

And with that success I want us to continue to build on that.

I want us to continue to coalition build.

I want to see our numbers and our interactions grow and grow.

I want to make sure we're including all sorts of people with disabilities and people ageing in that process.

IL world we sometimes leave out people who are aging.

We sometimes leave out people with intellectual and developmental disabilities.

People who may be don't actually hear, get their voices heard.

People who have had guardians since the minute they turned 18.

Okay?

People who have never had a chance to speak their voice.

And that's why I want Centers For Independent Living involved in this.

I need why I all to reach out people we have left behind in the past and setting rule is a huge part of that.

So I want to also let you know that the work we've done so far on this, when we came on board and started it there was this feeling of can we even be hopeful that anyone is going listen to us?

What's the point?

But I want to tell you what the point is.

We have seen things happen.

When we very first started working on this our meetings with CMS, they weren't all, you know the way they viewed things may have not been the way we in IL movement would want them to view us.

Maybe we weren't really been heard.

We were at the table or in the room, but we were kind of like a check box.

That ain't the case any more my friends.

We now are really engaged in the whole process with CMS.

What is going out to states and will be getting you will be able to see at the state level some of these letters that are coming from CMS and some of these action plans that CMS is KAPS as they are called corrective action plans that CMS is issuing to states.

You're going to see, you're going to see advocates' voice in those.

You will read them and know wait a second somebody was at the table who really got us heard.

And that somebody is y'all.

Advocates, that is who at the table and getting these things heard.

We need you CILs to be reaching out to communities that have never been heard before.

People with intellectual and developmental disabilities and group homes or day programs whose parents always speak for them.

That's where we need you.

Okay?

I will tell you that we also, ACL, me personally, Jill, I am

going to every state that is getting a review by CMS I'm going with CMS team.

I'm looking at every single provider that comes in that is put forward that needs a review.

And when we see that provider has issues across the board we're identifying that there are systemic issues in that state.

We are being heard.

We are going out there.

We are making a change.

I need you all to participate in this.

And when I see this change making happening I see you all putting in your time I see this happening in a whole new way, real, you know, old school coalition building.

You know take it back to the 60s and 70s.

I see that happening.

We see these changes happening.

I'm going to tell you, we have meeting now with CMS where advocates from state get together and they identify all of these issues.

They meet with CMS with us.

This real grassroots work.

They come forward lots of times the advocates do and they say hmm, you know I saw the list on providers that need to be looked at.

You know, we need these, here's a couple more providers that need to be looked at.

Heir ours back up.

Here's our reason.

Here's some systemic issues we see in the state where we feel the settings rule is being violated.

I'm telling you we go out to those places then.

We add them to our list.

I, me, I put my eyes on those places.

I come back, we write solid reports.

And the staters that information.

Didn't even used to be the states were going to have a public any kind of public documents around it.

Yes.

Send letters to states about it, yes we're going to say here's the concerns we have.

Now, those are going to be public.

Y'all can look and see what you've done.

How your difference is what the work has made a difference.

How states are going to have to respond to that.

I appreciate your time, your interest.

I'm really glad you're here.

I want to see us go places.

I want us to go there together.

Go far beyond this.

Thanks.

>> Thank you so much commissioner this Abbey from APRIL.

We've had a few question and answers come through.

This question was for Amber.

The question is are your services available in ASL either that you an interpret or advocate who deaf or hard of hearing?

>> Hi.

This is Amber.

So we don't -- just to be clear, we don't provide direct services.

We're not a center for independent living.

But when we engage in activities with our pierce with disabilities when comes to a system change work oh disability listening session or community conversations, we always as best practice ASL and live captioning and always, always, always.

We also provide whatever accommodation are need are necessary.

Also to be clear, the past two and a half maybe three years now we've doing everything virtually.

There's not a lot we've gone back to in terms of on site or in person.

But in and when we do when we did before this they were any related accommodations we were hosting or conducting we also provided any on site or in person related accommodations which includes ASL interpreter and even live captioning at those

live events.

We have a policy around this that those are always provided.

>> We also doubled up our budgets for accommodation and supports because we wanted to engage consumers more.

We knew in order to do that successfully our peers were going to need accommodations to participate and engage.

So it's a really key piece I think to doing this work when it comes to advocacy around the HCBS seatings rule.

>> Thank you so much, Amber.

Jodie, I see that you are typing an answer to this question.

But I didn't know if you wanted the opportunity to answer it out loud?

Either way is fine.

The question is, how do you maintain or enhance communication equity for those with diverse needs to help them advocate for themselves?

>> I was, sorry my computer was freezing not allowing me to answer the question.

But as a center for independent living we have multiple assistive technology programs that allow us access to communication devices and whatever a participants needs to be able to ensure that their voice is heard.

>> Excellent.

Thank you so much.

As a reminder, folks are welcome to put questions into the

Q&A.

We do still have few minutes.

We would love to hear what folks want to know more about.

In the meantime, the recording and PowerPoints for this webinar will be added to the APRIL website under the advocacy tab.

So you can visit www.april-rural.org and select advocacy and you will see the information there.

>> We have a raised handed from Todd.

One second, Todd.

There you go.

You now have the ability to unmute.

>> Thank you so much.

Jill, it's Todd Holloway.

I'm curious have we considered any of these new HCBS rules when it comes to something you and I are very familiar with and that is people getting relocated due to disasters and ending up having troubles with Medicaid and other issues where they end up out of state?

>> Todd can you repeat that question I didn't get all of it were you asking about what happens in disaster when people end up out of state?

>> Yes.

In relation to HCBS, the new rules.

Do you see any caveats that would strengthen our position

about, you know Medicaid being able to even transfer across state lines where we worked with the today's Medicaid recovery act and looking at these new rules and how that would play out for somebody who has had to be relocated into another state?

>> So these settings rules are, they don't have any specific elements that would impact disaster at all.

I mean what impacts disaster and HCBS and how people can move across states has lot to do with reciprocity between states, about how, you know, HCBS is fund between state and federal funds and kind of prevents movement in that way.

There are some potential solutions around that.

But it's not related to the settings.

The settings rule is specific to who receives home and community-based services and what those settings how those settings are meeting the rule, making sure that people have the most basic rights in place.

So person has to move in a disaster from Mississippi to you know, Idaho to be with family, and they can access HCBS in that move, if that something that happens for them, then, you know the same ideas around settings and how people are able to get into the community how their civil rights are not impacted or impacted as the case may be would be the same.

It doesn't really relevant to the specifics of the settings rule.

>> Thank you commissioner Jacobs.

Sorry, excuse me.

Another question from anonymous attendee which says I worked for a shady care provider a couple years ago.

There is anyway to anonymously turn them in for bad practices?

I believe this is directed towards anybody.

>> Well I'll go ahead and answer that.

If you feel like a provider that you worked for is shady and you are familiar with settings rule you go read about settings rule, wow they are violating this, then I would say reach out to your center for independent living.

Reach out to your, you know, your SILCK, reach out to APRIL.

And say, this is I'm concerned about this.

I've looked at the settings rule can you help me look at this.

And then it something that could be made known, you know about that provider.

I don't want to get into a ticks of shady, not shady what that actually means.

We're talking about if you are concerns that entities violating the settings rule than this process that we're talking about advocacy to bring it forward this exactly the way you would do it.

>> Another question came in from misty, with regards to the HCBS settings rule and guardianship interference with real consumer input and their person-centered plan and consumer choice where they prefer to live not in headquarters nursing

home or assisted living but a community setting.

How can CILs assure consumers have input to the fullest extent possible?

>> So part of settings rule, one of the elements is did this individual actually have choice in where they live.

Okay.

So if they are in an HCBS environment and they are in an assisted living did they really have choice in this?

Were they given all the information they need?

Did they get informed choice?

If a person is living in a group home, how did this person choose this home?

What sort of process is involved around creating person-centered plans?

And how does informed choice play a role in that is this so that is settings rule, yes.

Looks at those things.

We, we when we go out we take look and look at person-centered plans.

Biggest way people are getting informed choice are solid person center planning process.

And having, information that comes to them through advocates, in particular people with intellectual and developmental disabilities.

People who are ageing that may be never been involved in this,

they just got older.

Now they need support.

Those are the areas where it is important for CILs, you all get involved.

And you make sure that the informed part of informed choice comes from you.

>> Before we close out any other questions is this I did want to read out, we had a great chat from Erica McFadden that says moving forward as you think about spaces your organization is in and what commissioner has said, what more can done to advocate for independent living in HCBS?

Starting HCBS settings rule and even beyond with your state's transition plans are there specific actions your organization can take?

Who else needs to be at the table in your state when it comes to HCBS advocacy and enforcing the settings rule?

Who do you need to make stronger connections with to ensure that IL is represented in every space involving disability as it applies to HCBS?

Have you met with your area agency on aging for example where a number of older adults are not aware of their rights?

How can you start with your own consumers?

If any are receiving HCBS services from provider for example, day programs, residential programs, job sites, have you talked to them about where their lives are like in these settings?

Are they aware of what their rights are?

Are their families, friends and allies aware?

Just wanted to make sure that got read out.

As we're getting ready to close, I also want to ask that everybody here take the evaluation.

It will be a link as you close out of the webinar today, you will see a link to the evaluation for today's webinar.

We really love to hear your feedback on what we shared here today.

And also, this is just the first part of this work.

We will have a part 2 of this session and a couple further conversations around this work.

So make sure to keep an eye out for that going forward.

Any last things anybody wants to share or say before we close out for today?

All right. Have a great rest of your day.