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HCBS stakeholder webinar

Job 34887-2

2:00 to 3:30ET

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>>CART Provider: Standing by.

>> do we have captions working.

>> Can you do a test for me, Dawn.

>>

>>CART Provider: I am standing by.

>> Do you see the captions?

>> I saw it pop up a few minutes ago.

>> Yeah, it seems it's working on my end now.

>> Okay, yeah, it's working. And we're recording this, correct?

>> Yes.

>> And I think there was one more thing I needed to know.

Who is going to start with the interpreting for ASL is that Rebecca.

>> Yes.

>> We weren't sure if there was somebody here who needed sign

interpretation right now.

>> Marcia: I wanted to start the spotlight since you're starting in like moments. I'm going to go ahead and I think I will be able to I'm going to launch the poll because I want to make sure you can see it. Possibly. Just to make sure it all works out properly. I'm going to lawn that now. Do you guys see that on your end.

>> Yes.

>> Lisa Tesler: One more quick question. I turned my camera on right before it's my turn to be spotlighted, correct.

>> Yes.

>> Leave it on until I'm not spotlighted and turn it off.

>> Yes.

>> Got it. And I'm after Kirsten. Got it.

>> This is Shawn when you run the poll maybe make sure they know to scroll down to get all the questions.

>> Marcia: Who is going to introduce the poll.

>> I'm happy to introduce it in the context of the welcome if you would like. Or Marcia if you would like to, that would be also fine I could just turn it over to you.

>> Marcia: I am the behind the scenes person.

>>

>>CART Provider: Standing by.

>> Kate Brady: Welcome folks, it's my pleasure to begin the voices of people with disabilities and older adults, strengthening advocacy in the HCBS settings rule webinar. My name is Kate Brady, I

work as a projects manager for HCBS stakeholder engagement in the national center on advancing person centered practices and systems.

Which is administered by the Human Services research institute. You will see on your screen today a welcome poll and we would love to have your engagement with that poll. It asks how you identify and you can check all options that apply. There's options include a person with a disability, a family member of a person with a disability, a person who provides direct support to people with disabilities or professional and disability services. An advocate and other.

If your answer is other, please feel free to put that information in the chat. If you'll scroll down in that poll you'll see that question number 2 is my employer is A and that's also a multiple choice question where you can check all that apply. And the options are community rehab provider advocacy organizations, state Medicaid agencies, state DD agency, skilled nursing facility or group home.

Federal agency, University, person with a disability, or family member of a person with a disability, and other. The third question is I am familiar with the home and community-based services settings rule. Yes or no. Fourth question, I have given written or public comment on an HCBS state-wide transition plan before. Yes or no. That is the extent of the poll. I would like to offer a quick visual description.

I am a middle-aged white woman with round brown glasses and short brown hair. I am wearing a dark blue scarf and white T-shirt with a blurry HSRI background behind me. I think we can, we'll leave that poll

up for a moment or two so folks can respond.

So this webinar is the first in the administration and community living webinar series on the role of stakeholders in ensuring high quality in home and community-based services. In this session we invite you to hear the vision, the administration has for advancing engagement. The stakeholders and there by the experiences of people receiving support.

We will look at the rationale for engagement, the pathways available for input and some model approaches for giving and receiving stakeholder feedback.

A quick overview of the agenda today. As you see we've started with the welcome and participant poll. Then you'll hear from the principle deputy administrator and as the acting secretary of aging Alison Barkoff. Then the commission of ACL's administration on disabilities. Then I will provide you an overview of HCBS rule settings stakeholder engagement. Then hear from senior policy advisor Nancy tell letter to speak about model approaches to stakeholder engagement. Hopefully we'll have time for a brief Q&A and a closing poll. Some logistics you will see you are muted. You can use the chat feature and the Q&A feature to submit questions here. We are providing both CART transcription and ASL interpretation. So hopefully you're seeing those pinned on your screen. The webinar is live captioned in English. If you need to pull up those captions you just want to click the CC button on your screen and that

will pull up those captions and as you've seen we are including polls and would love your engagement. It helps us to know who is here and what your needs are. So we would love to have your engagement there. All right.

It is now my pleasure to introduce Alison Barkoff. Alison was sworn in as principle deputy administrator on January 21 and currently serving as the administrator and secretary for aging. She provides executive leadership and cooperation for ACL programs nationwide and serves as an advisor to HHS secretary Bocera on things that impact people with disabilities and older adults. Alison is a lifelong advocate for community living

both professionally and personally. She is the sibling of an adult brother with developmental disabilities and worked alongside her brother and parents from an early age to advocate for disability rights in her home state and later across the country. She graduated from Emory University School of Law, became a civil rights attorney and has worked since then at the forefront of national efforts to expand home and community-based services that make community living possible.

Alison appeared before Congress and the U.S. commission on civil rights and has been a part of countless coalitions of people with disabilities and older adults and advocates prior to joining ACL.

She served as special council for the homestead enforcement in the civil rights division of the department of justice. Held leadership positions with the centers for Medicare and Medicaid and directed advocacy efforts at both the center for public representation and the

Basal center for mental health law. Please join me in welcoming a true champion for people with disabilities and older adults, Alison Barkoff.

>> Alison Barkoff: Thank you so much, Kate, and welcome everyone and truly thank you for taking the time to join today's webinar. Let me start with a really quick visual description. I'm a middle-aged white woman with curly brown hair wearing a gray blouse and a Blazer and I have a blue background with an ACL logo behind me.

Just so no one is confused, we have Q&A but our chat is disabled so just wanted to make sure people knew that. For those of you who aren't familiar with the administration for community living or ACL, we're an agency in the U.S. department of Health and Human Services and our mission is to ensure that all people have the opportunity to live and participate in their communities regardless of age, type of disability, or level of support needs.

And I am so thrilled today that we are doing this webinar on the Medicaid home and community-based services settings rule or HCBS settings rule because it is really critical to our mission. I am thrilled that over 1,000 people signed up for today's webinar from across ACL's disability and aging networks, advocacy organizations, and most importantly people with disabilities, older adults, and their families are joining us today.

Today's webinar is about how to elevate your voices as states are implementing the HCBS settings rule and as Kate mentioned this is just the first in a series of webinars that ACL will be hosting. For those of you who aren't familiar, the goal of the HCBS settings rule is to

ensure that everyone receiving home and community-based services has the full benefits of community living. It's truly a transformational opportunity to assure that your state service system

Support you to have the life you want and to be a full and valued member of your community. At the same time at its core it's really about some very basic human rights, rights that other people take for granted. The ability to choose when you go to sleep, what you eat, who you live with and what activities you want. And so many of you over the last 8 years have been giving input and working in your own states on implementation of the settings rule.

We've made a lot of progress together but there have been delays of course due to COVID and COVID has made this rule more important than ever. Home and community-based services are so critical. COVID showed us that the risk of institutional settings is so high with more people dying and infected from COVID in nursing homes than any other type of setting. COVID has had such a significant impact on our community service system and we are seeing people have lost access to services and seeing our direct care workforce put under further strain through this crisis. COVID-19 has created an unprecedented opportunity for us to advocate, to expand home and community-based services and as we are starting to move past the worst of the pandemic, it's up to all of us to make sure that all home and community-based services including new services that are being stood up because of new investments by Congress meet the requirements of the rule. And this time is really

urgent as you will hear in more detail today. The deadline for states to implement the rule is March of 2023. But that's not the end. Even once the rule is in place, we have work to do together to make sure that there is ongoing monitoring and that systems continue to comply with the rule.

By working together, we can achieve that goal of community living for all. So I just want to touch on why we're doing the webinar today and what our goals are. As I said, this is really about how to elevate your voices. People who receive services and support and their families know best about what's working and what isn't working in your own state.

And your input is critical to this rule being implemented successfully. It's not just good to have your input, the rule actually requires your states to get input and to respond to stakeholder input. And through my many decades of working both personally and professionally, I know the value of advocacy and how important it is that we make sure people who are most impacted by policies are at the table and have the tools and supports they need to make a difference. I did this work before I joined ACL and when the rule first came out working with national advocates to make sure people knew about the rule and had tools to give input. And I am so pleased that in joining ACL, my colleagues here share that same priority in making sure we are supporting stakeholder input.

And we are very uniquely positioned to help support this as you'll be hearing from speakers today by leveraging ACL's disability and aging



networks. Who are trusted voices in communities across the country.

And we've really put our money where our mouth is. As Kate said, we have provided funding to the national center on advancing person centered practices and systems or NCAP's to really begin reengaging our networks and other national advocacy organizations to help support people with disabilities and older adults across the country.

We have brought on national advocacy groups as part of this work including the national disability rights network, the association of the University centers on disabilities, the national association of councils on developmental disabilities, the autistic self advocacy network, the self advocacy resource and technical assistance center, the national association of state-wide independent living councils and the association of programs for rural independent living.

Each of them bring a unique perspective and will really, really help us support all of you in engaging. I'll just say that our goals over the next year include building on and amplifying and doing what we can to support the voices of people with disabilities and older adults around the settings rule to make sure we're working together to look past March 2023 about ensuring that there is ongoing monitoring of the rule and big picture we're looking to really increase the awareness of people who are receiving home and community-based services on what their rights are and to create the knowledge and the advocacy tools for engaging in state based policy much broader than the settings rule, really everything about home and community-based services. As you'll hear from Jill in a few minutes, we really are looking long range to

support you. With that, I will thank you again for being here, for all the work you've already done, and for what you'll be doing together with us over the next year and beyond. And I'll kick it over to Kate to briefly introduce Jill who will provide a few words.

>> Kate Brady: Thank you so much, Alison for your leadership. So it's my pleasure to introduce to you all Jill Jacobs the Commissioner of the ACL's administration on disabilities. Jill brings to ACL more than two decades of professional experience managing disability services organizations analyzing policy and working towards improved health and disability programs and surfaces.

At local, state and federal levels. In addition she has worked with disability justice groups, disaster relief organizations and advocates to organize healthcare, human rights, and disaster relief initiatives in support of the most marginalized communities. Jill also brings to the role extensive lived experience both as a person with a disability and as the mother of two disabled adults. Jill joins ACL from her position as the executive director of the independent center of northern Virginia, a center for independent living. In that role she drafted and successfully advocated for the passage of two state laws to explicitly uphold the civil rights of people with disabilities, developed innovative approaches to providing services and supports to people with disabilities during the COVID-19 pandemic, and overhauled a number of processes and systems to both increase revenue and improve overall operations. And with that, in the interests of

time, and our ability to hear from Jill I'll pass it to you, Jill.

>> Jill Jacobs: .

>> Unmute, remember to unmute. I hope you are all well today, hello everyone. I want to first of all figure out where my comments went. They seem to have disappeared so give me a moment. I apologize. So I want to thank everyone for being here today. I'm very grateful for the opportunity to speak to you all.

Let me describe myself. I am a white woman middle-aged I have sort of reddish brown hair wearing a black sweater with cherry's and I am in my office with a bookshelf and artwork behind me. I am very happy to be here. I'm grateful that all of you showed up today and want to hear what we have to say.

As Alison said, the HCBS settings rule is extremely important. It is set standards around rights that many people with disabilities don't experience and for many, have never experienced. These include such things as having a lock on your door where you live, being able to access food when you are hungry, having a choice of the foods that you eat. Determining when you want to have visitors and who can visit you and how long they can stay.

How you might want to decorate your space. These seem so basic, they seem like really basic things. Most of us might not even think about them because they are so basic. But for many people with disabilities in our country who use home and community-based services, their everyday lives don't include these basic rights. So I ask that you get involved in the home and community-based settings rule process.

It's imperative, it's important, and we need you.

A key tenet of the disability community is nothing about us without us. When it comes to the settings rule, including the real stakeholders, the most important stakeholders, people with disabilities in the processes of requirement. But at ACL we believe, no, we know, that engaging with the people who need and are asking for services, in other words with people with disabilities is the best way to develop policy and the only way to turn that policy into good, solid, real programs that that are meaningful, inclusive, equitable and that truly achieve community integration and inclusion.

I want to share with you some specifics about how we are approaching public engagement in terms of the HCBS settings rule and I also want to explain our overall concept and our overall concept is kind of a long game.

So long game. We want to make sure that HCBS is what we, people with disabilities need. We want for disabled people, us, to feel ownership of HCBS. Because HCBS is the key to having real lives. To that end, we hope to educate, inform, and create a large community of people with disabilities who understand what HCBS is and what it is really supposed to be about.

Home, community, living, living our best lives, right. So what would living our best lives look like? What kinds of tools, supports, services are needed to get our best lives? What are the mechanisms, systems in place to deliver those supports and services? So something about ACL you all might not know, we are a federal agency dedicated to

advocacy, to the concept of change, and to the truth that change comes from people.

So we want to inform, engage, and give people tools that they need to the part of the process. We would like to see a cadre of knowledge filled advocates engage fully in making change happen. And we hope to see numbers of participants of change makers grow and grow and grow. So I'm pretty sure most of you here when I talk about growing, growing, growing our cadre of change makers, I envision it bigger, bigger bigger and I'm pretty sure

most of you here are a lot younger than me back in the 70s there was a sha poo commercial when I was a little kid and it started out with one person talking about how awesome the shampoo was and she wanted everybody to know. What did she do she told two friends and told those two friends to tell two friends and those two friends were supposed to tell two friends and pretty soon the TV screen was populated with little tiny pictures of all these people

who knew about the super awesome shampoo, right. That's what we want to do. We want everyone to know about advocacy, about advocating for the HCBS settings rule, and to play the long game of changing HCBS and making sure we own HCBS. Now, I know that shampoo commercial and the idea of two people, two people, two people might seem kind of naïve and maybe to policy folks maybe a little silly or grassroots

folks out there doing advocacy a long time, activism a long time may be a little rudimentary. Okay, but I know that this collaborating, building, growing, educating each other, coalition building, these are

the basics of change making. And if we do it, we have the keys in our hand to change systems. We need to participate and that's what we're asking you to do.

We see advocacy around the HCBS settings rule as a starting point. And through it we hope to catalyze individual level engagement. Around the settings rule, we want you all to make public comments and we want you to tell two friends, tell two friends, tell two friends to make public comments. We want you to be talking about this everywhere all the time on socials.

But more broadly, for any state or federal program that provides programs or services for people with disabilities and older adults, we want you all engaged. So again, we see this, the settings rule work as a starting point and we're not just talking about it. We are funding it at ACL. That's what this webinar and subsequent webinars and activities is all about. Our hope is that ACL's networks all of you are our networks, and people with disabilities with whom you engage every single day can be our boots on the ground. You know these settings and you know the people in these settings who are using HCBS services. Because you are the people. You are the collaborators, you are the coalition builders, you are the change makers. It is early days right now to talk about the results of our ACL's public engagement but I'll tell you that the energy and interest we've seen particularly in states engaged in something called heightened scrutiny which you will learn about has been immense, huge, and we're learning really important things from

folks on the ground about their experiences related to settings rule implementation. I'll say again, I can't underscore enough how important we think it is to ensure that people receiving services are at the table, not only at the table but the key people speaking at that table being heard at that table and being involved in what happens.

At ACL I promise you we are in it for the long haul. We want to amplify your voices and we genuinely think that states, provides, individuals with disabilities, their families can be most successful when collaborating. So let's get started. I will turn it over to Kate. Let's hear from our team. Thanks.

>> Kate Brady: Thanks so much, Jill. All right folks we're going to take just a few minutes and do an overview of the what and who of HCBS. So what are home and community-based services? Those are supports, employment, transportation, home healthcare, such as medications, housekeeping, in home therapy like PT, OT. Activities of daily living, bathing, dressing, going to the bathroom, cooking, finances and assistive technology and home modifications.

In 2018 more than 4.7 million people received Medicaid funded home examine community-based services and each state has it's own system and decides which populations they will offer HCBS waivers to.

Some of the core requirements of the CMS HCBS final settings rule are that every state must ensure that services meet the minimum standards for integration, access to community life, choice, autonomy, and other very important consumer protections. Such as the requirement of person centered planning.

By March of 2023 as Alison mentioned, states must have received final state-wide transition plan approval. All states and settings should be fully compliant with the following regulatory settings, including privacy, dignity, respect, freedom from coercion and restraint and control of personal resources.

In terms of provider owned and controlled residential settings, the requirements are a lease or other legally enforceable agreement providing similar protections, privacy in your home including lockable doors, freedom to furnish or decorate, access to food at any time, access to visitors at any time. Physical accessibility and a person centered service plan.

That documents any modifications to the regulatory criteria. States do have the option to submit corrective action plans. These flexibility allow for CMS to authorize caps to continue federal reimbursement of HCBS services beyond the end of the transition period if they need additional time to ensure full provider compliance.

So areas where CAPS will be allowed are areas of broader access to the community, opportunities for employment, option for private unit, and/or choice of a roommate and choice of non-disability specific settings. And states have to be able to show that their policies and procedures reflect the settings criteria. That they have made and they have made efforts to implement the criteria to the fullest extent possible.

So the reason we are here today is to talk about what are your engagements for opportunities for engagement and those include the



state-wide transition plans. If you're looking to see whether your state's transition plan has already been approved or is available for comment, you can access that link which we'll also get for you in the chat. States also have things like the heightened scrutiny package. This heightened scrutiny package

identifies sites states anticipate may not comply with the rule. And currently CMS is identifying states to do site visits, to evaluate these items further, and there are opportunities for advocates to be involved in those heightened scrutiny site visits through stakeholder calls.

In the future, we anticipate corrective action plans although in the required to be available for public comment, we encourage advocates to be in communication with their state Medicaid agency and to express concerns and responses to corrective action plans.

And last but not least at all, as we build your engagement with HCBS settings, we anticipate that advocates will have insight about waiver amendments and renewals, new service provision, and we encourage you to stay engaged and also provide comment in those settings. What do we mean when we say stakeholders? Well, it's a broad group and you heard from Jill about the importance of your involvement.

And that includes individual people with disabilities, their families and neighbors, also advocacy groups including parent groups, sibling groups, self advocate groups, state-wide independent living councils and centers for independent living and the many protection from harm resources that state protection and advocacy organizations ombudsmen and adult protective services.

So some when we think about engagement we don't just mean public comment and you're going to hear some great examples from states around the country in just a moment but a myriad of opportunities exist to engage in providing feedback regarding your experiences and the experiences of others in their home and community-based services.

You can show up and give in person comment. You can submit written comments, you can do that through your DD council or another organization that you're affiliated with. You can coordinate templates for others to use and submit comments and provide guidance so people know the framework for submitting a robust comment.

You can consult with partners and submit joint comments and of course you can call your legislators and your elected officials.

So we have created an opportunity to hear from you about the ways that you have been engaged in the HCBS settings rule. And we would love to see your comments in the jam board on the screen here. This feature will allow you to create little post it notes and write information for us about what you have been doing in regards to engagement.

We'll take that and turn it into a graphic and disseminate it after your response. So we would love to have you use that link and participate in that way. And in the interest of time, I am going to turn it over to Nancy Thaler, senior policy advisor for the administration on community living. Nancy will be guiding us through the conversation regarding state approaches to stakeholder engagement. Nancy comes to ACL having previously been the state director of Pennsylvania for 20 years. The CEO of NASD. The director of quality

at CMS where she also led the development of the HCBS waiver application, and Nancy also is a parent and spent eight years as a DSP including four years as a live in-house parent. So it's my pleasure to turn it over to you, Nancy.

>> Nancy Thaler: Thank you, Kate, very much. I want to note for people the PowerPoint everybody has been asking for is in the chat box now. There is a link and you might want to look at it because all of the states that are going to present have parts in the PowerPoint and you might find that very useful. So while you are trying to download the PowerPoint out of chat, just let me say my job is pretty straightforward. I am going to introduce the four states of the speakers

and I'm going to do the introductions rather briefly and they can say more about themselves. Speaking of introductions I should say to you that I'm an older white woman who has got very, very short blonde hair, a dark maroon shirt with a scarf and I have the standard background very plain blue background that has the ACL logo on it.

So going back to how we'll go about this, I'm going to introduce the four states very, very briefly who the speakers are, and then they will do their presentations and I will kind of try to do a little summary or point to points of interest before we move on to the next state.

So that said, we're going to start with Vermont, and our presenter is Kirsten Murphy who is the executive director of the DD council and Kirsten I'm going to hand it over to you. It's a real honor to be here. As Nancy said I'm Kirsten Murphy for visual I am an older white woman

I have salt and pepper hair but mostly salt at this point. I am wearing a black and white textured jacket and I have large eyeglasses on. There's a blurred background behind me.

So I assume I just ask to have the slides advance. So we could go to the next slide. I think all of us started with this thought of the foundational value of nothing about us without us. Everyone has said that so far. But what was behind that is of course this practical reality that I don't know what I don't know. Right. That self advocates and families who are living themselves or have a loved one living in a home and community-based settings are the ones that can bring the stories to us so that we can understand where the gaps are, where compliance is needed, what's going well, what isn't. Just a quick example. As a council member I run the DD council here I have a wonderful council member and he told a story about well, he's quite a foodie, right, he loves to eat, he's a wonderful cook. And he was placed in a home and community-based setting and his, the family with whom he was placed was vegetarian and they wouldn't buy him in I meat. This would no longer be consistent with the expectations of a home and community-based setting where this individual has a right to the food of his own choice. So those are the kinds of fine grained details that we so need from our colleagues who are people with disabilities and their families.

We can go to the next slide. So for the developmental disabilities council in Vermont we think of our role as having a three C's we're a conduit for information, we're a convener of stakeholder

meetings and various other gatherings, and we are a composer of public comment. We often try to get out in front in all of these activities.

So it keeps the pace at our office kind of high. Because we want to be rapid in responding to the latest events of the day and in that sense control the conversation a little bit. Out of the gate as we begin to pull in all of our families and self advocates and give them the tools they need to speak to the state.

So next slide. I like to start my dialogue with state partners often by reminding them that for DD councils anyway this is in your assurances. Your state has promised that you as a DD council will be a part of quality assurance activities. So section M of your assurances the council will participate in the planning, design or redesign and monitoring of state quality assurance systems that affect individuals with developmental disabilities every five years your agency signs that and you sign that and that is an agreement. And so if we're not being invited in, we invite ourselves and we say, well, this is our role, this is what Congress expects of us.

Next slide, please. So how do we do some of the nitty-gritty here because this is really work. We work hard in my office. And one of the places where that starts is becoming subject matter experts. We read everything related to the home and community-based settings rule. Not just the state transition plan. In order to be really on top of this, we needed to know what our state Medicaid waiver said.

What all the CMS guidance has been, especially letters to state Medicaid directors. What are state quality strategy is because that's

where much of the compliance resides. We made sure that we read all of these documents and became experts on them. As we watched this, we've been watching this unfold since 2014 and even before that.

We use every opportunity for public comment but that doesn't always mean formal public comment. We do submit formal public comments but we also try at most advisory group meetings and Vermont has a lot of advisory group meetings, we try really hard to find an opportunity to reiterate our message in the context of those meetings because often some of the trends and CMS rules come up in those meetings and we will be the first to raise our hand and reiterate the importance of the settings rule, the fact that the deadline is coming up on, in March of 2023, and we share, we also share our comments widely when they are written. We make sure that they are not a conversation just between us and, say, the state quality director who is written our transition plan. It's a conversation we want a lot of people to see as being had.

So we make sure that we share that widely. Next slide I think. We build partnerships with all of the disability communities, and that would not only be the formal DD network but we have really pulled an independent living a lot in this conversation about home and community-based settings.

Because that touches so much on their community as well. We often start a conversation with other allies by bringing draft talking points to them. We don't know that's going to, we see that is just a beginning of a conversation. We often work with them together as we pull in broader meetings with self advocates and family members and begin to

hone the message based on what they have to tell us.

They are the ones with the good stories. We have made a real effort to take a lead in explaining the settings rule in plain language because it is not, it's almost comes as a surprise to some of our self-advocates that the rules are changing so profoundly for them.

And I know has a reputation for very fine services and that happens in many cases but for many people the idea that you can have the right that you do have the right to have a visitor at any time of day and a provider owned setting is life changing. It's life changing and it is really important for people to come to understand those new norms. In a language that makes sense to them.

People often sit back and kind of say oh, well the state, gosh the state hasn't really invited us to the table. We don't work that way because that invitation might not be coming. Our state workers not out of meanness but because our state workers are overworked. Instead we organize town meetings and have done this around the home and community-based settings rule and then we invite the state to come and listen.

And when we do that we prepare very carefully for those opportunities. We look for stores in advance and make sure those individuals are there and make comfortable sharing the stories they have. We coach speakers in advance. We help people with plain language. And then we follow-up after the meeting with a written summary and key points that we hand back to the state so we make sure there's a record

of the important points people share. Next slide.

So I like to talk about the home and community-based settings rule as a story and when I'm explaining it to people I start all the way back with Olmstead, and I tell a story about how we went from Olmstead to reaching out to people to find out what home and community-based living really meant and then CMS began to promulgate these rules in 2014, and then low and behold there's a straight line through to today where we are finally coming up with a deadline and the transition plan have to be a reality now in our states. So similarly, and in that story I want to really recommend something to you all while I have you. ASAN the autistic self advocacy network still holds a foundational paper which is titled self advocates describe the meaning of community living and if you want to see where some of the rules in the home and community-based settings rule kind of came from where the particulars came from, this is a wonderful short read. It's an example of bringing together self advocates who shared truly what it meant to them to live in the community. And what it meant wasn't about a particular building, it was about the quality of the life that they had.

And I find it a really inspiring way to begin to show people what is so aspirational about this home and community-based settings rule. Similarly, we've a long story in Vermont. In 2014 when the rules first came out, Vermont was not, still not in compliance with the person centered planning component of the rule. Because we actually do not have conflict free case management. And our state said nonsense that



rule doesn't apply to us.

And we begged to differ politely and continued, like I said, to bring that up in every single meeting that we had an opportunity to bring it up to. We put it in every piece of public comment. Eventually the state said well maybe it does apply to us but we're going to ask for an exception and maybe we can get a different model, maybe we can have more choice and not have to have conflicting interest case management. We said I don't think so.

But we kept bringing it up. We kept bringing it up and eventually CMS said to the state no, no, you're under a plan of correction now you do have to comply with this rule.

All along the way we began to reach out to our colleagues in Washington, even to ACL's policy people and eventually we're allowed to put some of our thoughts directly in front of CMS because people were telling us example after example where conflicts of interest had operated not in their interest but had caused them to be disadvantaged in negotiating with the provider or their agency or their home provider.

We took that lesson and are doing the same thing again with the settings rule. We are bringing it up at every meeting, we are holding those town meetings. Vermont was selected for an early visit by CMS. We were very pleased because we had already established a relationship a little bit with ACL and with Nancy here and with CMS to be invited to bring stakeholders into conversation directly with CMS.

That's very powerful. I never thought in my career I would get to really be able to directly speak to our Medicaid liaison but we did.

And people in our audience were prepared to share the stories that really needed to be heard. And that's how we're continuing to operate, those relationships that we built have really paid off. I think in the interest of time I'm going to stop.

>> Nancy: Finish your last slide.

>> I don't think they are important I want to stop right there thank you very much.

>> Nancy Thaler: Really, really great. Your PowerPoint slides are almost a workbook or guidebook for community engagement. And I think that conduit for information and convene our stakeholders and propose public comments is a really great way to describe a role and maybe one of the favorite things if you're not invited to invite yourself. Really great. We're going to go through all four states and then we'll have a Q&A section.

So I'm going to introduce Pennsylvania next. My friend Lisa Tesler who is the executive director of the DD council and Sally Gould tailor whom I have not had the pleasure to meet but congratulations on your appointment to the temple U Lisa and Sally the floor is yours.

>> Lisa Tesler: Thank you, Nancy. So good afternoon everyone. My name is Lisa Tesler and I'm the executive director of the Pennsylvania developmental disabilities council, and a visual description, I am a middle-aged white woman with shoulder length brown hair. Today I am wearing a V neck yellow sweater, a necklace with green and blue colors and I wear glasses. I have a green background with the Pennsylvania developmental disabilities

logo behind me.

>> Sally Gould Taylor: Good afternoon everyone my name is Sally Gould ta Taylor I am the executive record temple University. As a visual descriptor I am a white woman in my 40s with a round face, dark black hair pulled back wearing a white colored shirt with a blurred background. I will hand it over to you Lisa to start for Pennsylvania.

>> Lisa Tesler: I'm excited to be here today and talk about how Sally and I and our organizations partner to engage with individuals and families. So the first thing I want to talk about is the information sharing and advisory committee. This is a committee that's led by the office of developmental programs.

The office of developmental programs provides services for people with intellectual, developmental disabilities in Pennsylvania. It is guided by the principles of everyday lives which is a philosophy and a set of values that were developed by people with disabilities and their families.

That kind of sets the standard of quality that the system follows and was a collaborative effort and agreed upon that kind of sets the standard for what quality means for everyone who is engaged with the system.

It's defined by the people and families. And this group focuses on the quality and they developed a set of recommendations that talks about how to improve quality of life and outcomes for people. And some of those recommendations align with the home and community-based final rule. Things like increasing self determination, choice and control.

Increasing community participation and employment. And increasing opportunities for different types of housing and community options. So that group comes together every other month. It's a broad stakeholder group. It includes all of the representatives from the DD network. So the developmental disabilities council, the institute on disabilities at temple, and disability rights Pennsylvania are all members of the group.

It has representation from self advocates and families. There are at present 14 different individuals with disabilities and families represented on the group. And that group then participants in all of the discussions around what are the policies and practices that the office of developmental programs puts in place, looks at data and measures an outcome and makes recommendations for improvements and strategies to

the systems to measure how they are doing. And they produce an annual report every year that is public so that everyone who is engaged in the system knows what's going on and knows what progress is being made.

I don't know, Sally if you want to add anything about how that group works and functions?

>> Sally Gould Taylor: I would just add that this group works in collaboration with and in response to kind of the decisions and guidelines that are being made in a response to the development of the state plan, the transition plan, putting out plans for heightened scrutiny, and all of that type of stuff. So it really is a dialogue happening back and forth.

>> Lisa Tesler: Next slide. So one of the other important things that the council and temple has done together over the past five or six years is after the final rule was passed in 2014, the council recognized that there was an important opportunity here to create real transformational change for people with disabilities and their families.

If the final rule represented an opportunity for people and families to really have fully inclusive lives in the community in ways that we're currently not available. The way service delivery and the models that were offered in Pennsylvania were not giving access to the broad community to the same extent as people without disabilities.

Folks were not having the same experiences. The same opportunities for employment for work for freedom and choice and control, autonomy, to make choices in their own lives. So the council issued a competitive grant as part of the five year plan from 2017 through 2021. And they wanted to make sure that individuals and families who are served by the system had the opportunity to engage in advocacy to the education and information they needed and to engage in the monitoring of how the implementation of the rule would be implemented in Pennsylvania. In the hopes that their lives would be better if the rule could be implemented in a way that led to really significant changes.

In how services would be delivered. Please temple won the award and so I'll turn it over to Sally to talk about what was some of the

work they did while in that five year period.

>> Sally Tesler: Absolutely. The institute was awarded this grant and we partnered with several stayed with the organizations including disability rights Pennsylvania, the Pennsylvania health law projects and self advocates united as one called SAU1 to carry out the grant. The four large tenets of the grant were sharing about the HCBS settings rule with Pennsylvania's information sharing advisory committee as well as gathering feedback on the rule.

Implementation from the ISAC members and other community members. Forming an HCBS advisory committee consisting of key community members including people with disabilities who receive HCBS waiver funded services and supports. And members of this advisory committee and others then went onto form a state-wide advocacy coalition which we call the coalition for inclusive community which we'll talk little bit about on the next slide. Also part of this work was assisting self advocates and families to develop and submit comments to the department of Human Services around access to quality HCBS and community living HCBS services and community living. As well as providing people using HCBS with a platform where they could share their personal stories about the importance of quality services in their lives.

And the highlighted link on the screen which you can look at another time will take you to some individual stories of Pennsylvanian's who are sharing how HCBS quality services impact their daily lives.

And those Pennsylvanian's were supported across Pennsylvania but

also a federal level. So as I said one of the things that came out of that project was the development, the recognition people in Pennsylvania wanted to both think about, respond to and address the transition plan around the HCBS settings rule but also they saw it as a larger picture.

They wanted to create a coalition for inclusive community. Out of this work came a community, a group of community members across the state including all three of the DD network partners as well as many advocacy leaders from the self advocates organizations state-wide family advocacy groups, centers for independent living and the ARC of PA. They came together to talk about not only the implementation of the new settings rule and how Pennsylvania was responding but also to talk about other issues around community choice and quality. And for Pennsylvania over the last few years one of those large issues has been supporting the closure of some state centers, state institutions.

Move to the next slide.

>> Sally Gould Taylor: Some of the work that council and temple partnered together to do is we create model comments for other organizations, individuals and families. So when there are opportunities for public comment on waiver changes, waiver amendments, the transition plan was just our comments were due yesterday. The community comes together usually the three sisters network DD network sisters come together or the coalition comes together. We get feedback and we create model

comments that we can then distribute through our networks so that individuals and families have templates and information that they can use so that they can feel confident in submitting comments for themselves. Additionally, we convene small groups of families and self-advocates to talk about what the waiver changes or the HCBS rule means. Explain what the changes could mean one way or the other. And ask for their input and then support them to consider how they would respond and to provide input and comment to leadership.

And similar to what Kirsten said we do sometimes in the past preCOVID had invited administration and the office of developmental programs to some of those meetings to hear directly from individuals and families. And then Sally do you want to talk about the plain language resources.

>> Sally Gould Taylor: Sure, again, as Kirsten talked about and we all know a lot of language within the HCBS final rule is complicated. It's difficult but it gets to the heart of people getting to choose the life that they want. And so this means spending time translating the rule, translating some of the language into plain language or easy read access.

Making sure that the resources are accessible by screen reader. Making sure that the resources are getting to all of the individuals in the accessible modes that they need. And then the last piece that we do around this additional support is social media engagement. Providing examples, Instagram, Facebook, and Twitter posts people can then share. People can make their own by providing their own pictures



or example of how they are living their everyday lives.

But making sure we are pushing out this information in some of the new media or nontraditional ways as well. And I think that's it for us from Pennsylvania.

>> Nancy Thaler: Thank you so much and your contact information, thank you. There is a thing here across the two states about being a conduit information I think you two used the word convening and some new ideas about translating this very complicated rule to plain language. What a great resource for people and using social media.

So again, a template for a wide range of ways to engage and influence state practice. Thanks so much.

Alabama is next. And there will be three speakers. James Tucker who are the director of the disability advocacy program at the University of Alabama. Louise woods who is a founding member of people's first Alabama. And Vicki Turnage who does a lot of things but one of the things is she is could director for self advocates becoming empowered. So I'll let you three do a fuller introduction and people can hear your voices then. Thank you so much.

>> James Tucker: Thank you to everyone for being here, thank you to everyone who is facilitated this session and to all the stakeholders and advocates. Just a quick introduction my name is James Tucker, I am a lawyer, I am the director of the protection and advocacy agency in the state of Alabama. Also known as P and A as many of you know is one of the three DD network partners in the state as in many states along with

the USAID and the DD council. I will do a quick visual description. I'm going to do a thumbnail summary but in order to respect the time of everyone, what we really want to do is to facilitate a discussion today with my good friends and advocacy partners, Vicki and Elouise, it's great to see both of you.

Elouise, if you can unmute then all three of us can talk in just a minute. So I want to say a word about what the P & A has done in Alabama. This work is challenging. This advocacy is challenging in the state of Alabama. Alabama is a state with not many resources dedicated to public services.

So several years ago the P & A decided that as a strategic matter, we wanted to monitor the 1,000 HCBS settings in the state vigorously. We haven't gotten to all 1,000 but we've gotten to a lot of them. Our state invited two sets of comments. One in the fall of 21, so last year, and one this spring. Again, I just want to give you a thumbnail. In the fall we were told that our comments could only relate to each individual setting, not to the system.

So our P & A prepared a comment that eventually ran more than 700 pages long, and we commented on each of the more than 1,000 settings in the state. In the spring we were invited to comment again and we made something like a 50 page comment that was much more targeted and thematic and we're excited to be able to do so.

During both of those comment periods, we worked with a number of stakeholders from across the state, the P & A facilitated listening sessions with Elouise and Vicki, but also with many others. For

example, members of the DD council, the USAID, ombuds advocates and others. Some reference has already been made in Vermont and Alabama we vigorously advocated to ACL and CMS that an on-site visit occur in the state of Alabama.

And such a visit did occur here in August. We worked with individuals to be able to provide comments in a wide range of formats but I want to describe one additional consideration that we made just because I have not heard it described so far. When we described to members of the public that individuals could make comment, we had some members who said they were afraid to comment.

They feared that if their comment was known, that they could experience retaliation or harm. In that situation, we offered to each such person that the P & A would adopt the comment as our own with their approval and make that comment.

To one more way in which we facilitated a wide range of comments. We would be happy to make any of those resources available but with that, Vicki, I'm going to mute and back off and ask you, Vicki, if you could facilitate a discussion with Elouise. The thank you both for being here and participating today.

>> Vicki Hicks Turnage: Thank you, James. Elouise could you unmute yourself. Can one of the other presenters unmute Elouise, please.

>> Alison: Marcia can you unmute Elouise.

>> I can't she has to unmute herself.

>> Elouise if you look on the bottom left of your screen

there is a picture of a microphone with a red line through it. If you click on that, that should unmute yourself.

>> Vicki: Give her a second to do that. As Nancy indicated at the very bottom of your screen there is a microphone. Tap on it it looks like Elouise, ask if you could ask your niece to help you unmute yourself.

>> Hitting the space bar will also do it, one long space bar.

>> That's a great suggestion.

>> Vicki: We understand.

>> Elouise if you press the space bar the long button on your keyboard on the bottom middle, press that button.

>> Vicki Hicks Turnage: Let me introduce myself while I'm doing that. I'm an older white woman with Auburn hair with blonde highlights and I'm wearing dark rimmed glasses and I'm wearing a headphone. I have a red women's polo shirt with University of Alabama script A.

And my background is blurred. As I said my name is Vicki Hicks Turnage, and I actually run support coordination agency in the state of Alabama but I'm also the codirector of the SARTAC national self various center.

I have worked with safely advocates becoming empowered as an ally for many years as well as people first of Alabama. So when we get Elouise back on I'm going to talk with Elouise about her view of the HCBS rules. Elouise currently does receive services from the, one of the Alabama waivers and she was also involved in the writing of the

position paper with ASAN and self advocates becoming empowered.

That we have referenced today. Of the meaning of community for self advocates. Elouise, could you tell folks about why it's important for self advocates to be involved in learning about the HCBS rules and how you have talked with folks over the years about living at the community and things that are important to them and to you.

>> Elouise Woods: Can you all hear me now.

>> Loud and clear.

>> Elouise Woods: You hear me loud and clear. Hi.

>> Yes.

>> Elouise Woods: What you said now I forgot what you said now.

>> Vicki Hicks Turnage: Tell us about community and what it means and how you've worked with folks to talk to folks who make the rules in the state about the community and the rules.

>> Elouise Woods: Living in a community I thought it was very important to people who got a disability. I've been able to talk to people, tell people about rights. I would like to people to know what rights means. I tell them living in a community, get your right like going shopping, going to the movies, going to the store and just going to the park, just going to things line anybody else want to do.

And a lot of folks don't really understand because they don't know, they don't understand what we're talking about. But I think it's very important to people who talk to people to tell people about if you don't understand firsthand, repeat your words and make sure you're real

clear for them to understand because when you talk to people they might not understand a lot of things to you.

But you might have to tell them again. But like I said, I knew somebody in a home, I had my own place, that's my choice where I want to be. Do I want to live in my own place or do I need a roommate. And my choice is I want a roommate, I wanted to learn how to pay my bills. I want to learn how to go shopping. I want to learn to travel some things, go out of town sometimes. And just my money, put my money in anything I need I could go and get it. But a lot of people just don't know that. They don't understand the rights. They don't understand what's going on in the community and going to people and asking people. They just don't know. I want to be part of people first and people first is to teach people how to speak up to make your dream come true.

My dream came true because long time ago I told them I wanted to be in my own place. I did get my own place. I had me a job, I had my own money what I want to do with it but when you go into people like group homes and institutions, sit down and talk to people, they really don't know what that means. And you're going to read it like I said earlier you're going to really work with people.

Please understand them and they might don't ask you and ask them do they really know what you mean, what you are talking about.

>> Vicki Hicks Turnage: Elouise, are you saying that for, in order for people to learn about the HCBS rules, states have to help them by going out and talking with them, having some focus groups, self

advocacy groups, talking with them. And talking and understanding what these HCBS rules really are? Because I think you basically, everybody, all the self advocates that worked on this keeping the promise said these are just basically

our human rights, they are no different than anybody else. That you know, we have the right to live where we want, have people come visit us, eat what we want, cook what we want without the system telling us what we have to do is that kind of what you're saying?

>> Elouise Woods: Yes, uh-huh.

>> Vicki Hicks Turnage: What did you want to share about what people first of Alabama has done in the past about helping people speak out and tell people what they want?

>> Elouise Woods: Like I said, we had some, and what we do we talk about different stuff like some people want to know let me take that back. When we had a board meeting we made a list of some stuff. A lot of folks want to know transportation, jobs, home, money, and how you could have friends.

A lot of people don't have no friends. I don't know because they are scared to have friends. Or they are scared to go to the person. Or they don't really know. I met a lot of friends and a lot of friends told me we want to have some friends to go out sometime, go to dinner sometime, to go to the movies sometime. Or just go to the park and to walk around and have fun like anybody else want to have fun.

They really don't understand. Some people might get upset because they don't really understand and I said when you really, really

really going to talk to people, please to make your words clear and then ask them for you to talk to them. Do you realize, do you understand what I'm talking about. They might not said that, they might give you some kind of exercise let you know they don't really understand. And I think they are just scared.

>> Vicki Hicks Turnage: To summarize I think in terms of what seems to have been or is being effective in Alabama is the need to connect with self advocates and the people who are receiving services. With their families we would like to send messages to our state I'm blocking I'm sorry. Our department of developmental disability services is the need to listen the approachable, connect with self advocates.

Not to wait for, you know, to move us forward to make sure our, the information that's provided is in plain language and easily understood.

>> Nancy Thaler: Thank you, Vicki and thank you Elouise and James. Really appreciate it and I think you make the point that peer to peer, people oh to people is really important to explain the rule and interpret it. Want so we're a little squeezed on time so I'm going to go quickly to Georgia. And Dr. Alyssa Lee who is the public research and development research director which is the council on disabilities. Doctor Lee would you like to proceed.

>> Alyssa Lee: Thank you for having me. Excited to be here. My name is Alyssa Lee I'm the public policy research and development director for the Georgia council on developmental



disabilities. I am a young white female with short brown hair. I have brown framed glasses and I'm wearing a Navy dress with multicolored flowers and my background is blurred.

I think there's always advantages and disadvantages to going last. One of the advantages is getting to listen to all of my fabulous coworkers around the country and all of the wonderful working they are doing. One of the disadvantages is probably many of my talking points have already been covered which is wonderful sounds like we're doing similar work across states.

I'm going to be brief, cover a couple of additional points that I didn't quite hear and maybe turn it back over to you Nancy and see if there are last words before we end. I would say that one of the pieces, I don't think I heard, I definitely heard a lot of work around convening partner organizations and making sure that, you know, our communication is a disability network.

We're using one voice and elevating that voice. At all meetings in all ways making sure that community members including folks with disabilities and their families are getting the information in a timely manner whether that be through social media or town halls, forums, certainly in plain language.

I think one of the things that we've also utilized at the Georgia council is the technology platform that allows us to assist people in creating email templates so they can send public comment very, very efficiently and easily. We think of Mad Libs where you can plug and chug some of your information into a template that's already been

created. The other thing we are able to do with that platform is actually text our advocacy network so we can really have real time information the way most of us are receiving that now. Maybe we're not checking your emails frequently so we can send those texts so folks know as soon as it's made public that there's a public comment opportunity. And then I think last before I kind of wrap up one of the things that we also have worked on here in Georgia is sort of applying, I would say applying pressure to our state agencies to ensure that they really are putting forward opportunities for robust stakeholder engagement and not just for stakeholder engagement from provider agencies. So of course that's important perspective to receive but we really want to make sure that users of services, people with developmental disabilities and their families are also having opportunity to one, receive information from state agencies in a way they can understand but then also provide public comment and I'll provide two examples of the way that we apply pressure here in Georgia to make sure those things are happening. The first would be ensuring that there's a full 30 day public comment period. There is one instance in which the public comment period was open without proper notice so we actually advocated toward our state agency to make sure they extended public comment period so we could make sure advocates had ample time to understand the information and comment. And then the other opportunity was that there were some really great webinars being hosted by our state agency but they were provider focused and so we advocated to our state agency to ensure they incorporated an additional webinar that was focused on user

perspective and so that was focused specifically on Georgian's with developmental disabilities and their families who are users of the service so the state can kind of keep in their minds there is this full picture here of the information they are disseminating and it's not just a provider heavy perspective they sometimes take. Please and so we just wanted to make sure that not only are we hosting meetings but that we're kinds of applying the pressure that the agency's don't just rely on our organizations but they are also keeping that in mind themselves.

That was it for me. Simple and quick. And I'm going to send it back over to Nancy.

>> Nancy Thaler: Thank you so much. And everybody didn't say everything you were going to say. You had lots to add. I am going to wrap up and hand it back to Kate who is going to handle and manage the question and answer.

>> Kate Brady: Thank you Nancy and thanks to Vermont, Pennsylvania, Alabama and Georgia. So on your screen here are some resources. You can access those after the fact because we will email this PowerPoint in PDF form to all registrants. Some of you have already downloaded it from the chat. We don't have time to do a verbal Q&A.

But we will make sure to capture any unanswered questions and include that content either in a follow-up document or in upcoming webinars as this is the first in the series.

So at this time, I would like to ask that we put up the final poll

and that way we can hear from folks about looks like maybe that's the welcome poll that we've got right now. So we're going to want, there it is thank you for attending. So we would love to know what you thought of this webinar. It would help us immensely. We're asking was the webinar helpful in refreshing your recollection or to learn about HCBS settings rule.

Are you more likely to engage in advocacy organizing or other stakeholder activities, yes or no. Are you more likely to submit comments on the HCBS settings state transition plan after watching this webinar. So I see comments are coming in there. Responses. Thank you so much.

We would give that just another moment. And then we can close that and go to the final poll. It will just be one more I believe. And friendly remind to continue to populate that jam board that a wonderful Alixe Bonari after the email. You will find resources in the chat we will be sure to distribute. I think we can move to that final poll.

Marcia.

>> This was the only poll I had on here this was the last one.

>> Kate Brady: We are all set folks. Thank you so much for being with us today. Thank you to ACL for your leadership and I hope everyone has a lovely afternoon.

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