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Event Started: 10/30/2015 5:00:00 PM

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Please stand by for realtime captions.

>> Ladies and gentlemen thank you for standing by and welcome to the Implementation of the Home and Community Based services rule webinar and during the presentation of participants will be in a listen only mode. Should you wish to ask a question please use the chat feature the lower left-hand corner of your screen. If you need to reach an operator press star and then zero. As a reminder this office is being recorded, Friday, October 30, 2015. I would now like to turn the conference over to Joe Caldwell.

>> Thank you and good afternoon everyone. Thank you for joining today's webinar. Today's webinar is hosted by the Disability and Aging Collaborative and that is a coalition here at the national level that is over 40 national organizations, aging and disability, and we work together to try to advance long-term services and support policy, primarily at the federal level.

>> We formed about six years ago. Like I said, these are mainly national organizations but we started this webinar series as a way to communicate with state advocates working - working on this issues and the perfect example of that is today's webinar here at

>> The webinar today is really made possible with support from the community living policy Center at the University of California San Francisco. This is a research and training Center headed by Steve Kaye and funded by the Administration for Community Living and the National Institute of disability and independent living rehabilitation research, or NIDILR, and the views of the presentation are the views of the present users.

>> The question I get a lot is we get a copy of a PowerPoint? The answer is yes you will and you will get an archive of the entire webinar which will come later today. You will have it pretty immediately feel free to share that with anyone else who might be interested in could not make it today.

>> The other housekeeping issue is the way we will to Q&A today is through the chat function which is in the lower left-hand corner. You will see a box. Feel free at any time to submit questions and we will remind folks at the end to submit questions and will try to get to as many as we can.

>> I will do a brief overview of the webinar and I will turn it over to the speakers to sort of set the background a little more. This is a topic that has a tremendous amount of interest. On today's webinar there is actually over 850 people who have registered, you much from every state, their aging and disability advocates, people who work for state governments, service providers and health plans.

>> There is broad interest in implementation of the settings rule. We did a webinar about one year ago. That one had over 1000 people. At that point implementation was just starting to roll out in states had not done their implementation plans yet. And so now we wanted to circle back and really, you know, right sort of an overview of where things are at and what the status is and what the implementation plans look like in some of the themes that have come up at those, and CMS is looking at those.

>> I think you will find these webinars really useful. It is sort of advocates at the national level speaking to advocates at the state level that are really working on these issues. It is really to share information and encourage people to stay engaged. So the speakers, you have a great lineup of speakers. These are real advocates and people that have been working on the implementation and looking at the state plans.

>> We will start out with Nicole Jorwick, Elizabeth Edwards and David [ Name unknown ] with the national help law program, and advocate things that have emerged in the plans. We also Incorporated Dan Burland from the national Association of State Directors of development will disability services and Dan can provide sort of a state perspective. But also health advocates and state organizations that can really work together on this and what could be helpful in terms of the state perspective. I should also note that Dan is a cochair of the CCD long-term services and support task force. If you're not familiar with CCD that is another big coalition at the national level, actually over 100 disability organizations, so Dan cochairs task force and does a great job doing that.

>> So we have a lot of information to share and I think we will go ahead and get started. I will try over to Nicole to provide some of the background on the rule.

>> Hello everyone, glad to be with you here today, I will be presenting some quick facts on what the HCBS rule says and what it does not say and will be touting more into what is going on at the state level and then let you know what to do at the state level for advocacy.

>> Let me see if I can advance the slides, [ Indiscernible-low volume ] and so again we will be doing a quick review of the settings rule, what is going

on at the state level with the transition plan. I do want to make sure, I've seen people say that I need to speak up so I will turn up my volume and hope that will help. Please let me know if that is better.

>> [ Indiscernible-low volume ]

>> Okay, I will put it as high as it can go. Just going into a quick review of what the settings rule does say, CMS did issue the regulation for the HCBS rule and March 2014 and states had one year until March 2015 to submit a transition plan to CMS. At this point the transition plans are in.

>> What we are working with now is the CMS response to that letter and as of today's date not one state plan has been approved. It is important to note this rule applies to 1915 C waivers 1915 (i) waivers in 1950 (k) state plan options and it is important for all HCBS settings and it is important to note that if the state has a program up for renewal within this time that waiver renewal also has to align with the HCBS settings.

>> The agency BS settings rule - HCBS rule came in and it is in compliance with the ADA and it supports access to the community and it does not specify what settings do and do not qualify, it defines qualities of what makes the home and community-based settings. It provides one definition across authorities. It is important to note that the intent of the regulations is to improve HCBS and not to shut down settings.

>> It is meant to ensure that HCBS funding are being used in settings that are truly home and community-based. It is important to note in the work CMS is doing that the focus is on the individual's experience, the individual's home and community-based experience, when looking at different settings.

>> And HCBS does not cover settings that are institutional. Institutional settings include ICFDD, ICFIDDs, hospitals, obloquy run institutions, and the setting is presumed to have institutional qualities if it is a facility that provides inpatient treatment, if it is on the ground or adjacent to a public or private institution, and settings that have the effect of isolating individuals who are receiving this home and community-based settings. Or services.

>> CMS has provided characteristics of what must be part of a HCBS setting including the setting must be integrated and support access to the community, it must be selected by the individual from among setting options and it is important to note that the state showing tentative had a choice does not make a setting community-based.

>> We must ensure the individual rights of privacy, dignity, and respect and freedom from coercion are always being protected. And specifically each participant must have a lease or legally enforceable agreement for the

residential services, privacy in his or her unit with lockable doors, choice of a roommate, freedom to furnish or decorate the unit based on what the individual's preferences are, control of his or her schedule, including access to food at any time and rights to visitors at any time, and obviously physical accessibility of a setting.

>> Provider owned or controlled settings have an additional obligation that is any modification of the conditions I just listed must be supported by a need that has been specifically assessed in the individual person centered planning. Person centered planning is also an important part of the HCBS rule.

>> I see the question about making sure to define acronyms. It is also important to note that the HCBS guidance does include not only residential settings but also day programming as well as employment settings. Because to all settings that are funded using Medicaid waiver dollars. CMS has provided guidance on nonresidential settings and they provided that guidance in December 2014.

>> It is entitled Exploratory Questions to assist states and assessments of nonresidential home and community service settings. The document similar to residential guidance contains questions to serve as a tool to assist states and stakeholders to understand whether or not the quality is present in a particular setting as well as to assist in the development of the state transition plan.

>> That is one example of exploratory questions. CMS has provided quite a bit of guidance on this topic. Even if it is obviously sometimes hard to find an answer because we're looking at each individual's experience and we are looking at each specific setting. There is the nonresidential exploratory question, there is documents around settings that isolate, the transition plan toolkit, and also additional questions and answers.

>> Now I will turn it over to Elizabeth Edwards and she will go more in depth on what is happening at the state level.

>> Thank you, today will talk about where plans have been, what they look like early on and how they have evolved since then and focus on some of the trends that we have identified, and also what CMS has identified and their communication back to the state.

>> Just as a quick review, and I think that's Nicole mentioned this, CMS has a good website that has links to all the statewide transition plans and is updated fairly regularly to reflect whether or not the state has received a letter back from CMS, and as we go forward it will reflect any approvals that have occurred. I would encourage people to check out that website if you

are wondering at what is happening in other states. And there are also advocacy websites that are also tracking.

>> All the plans have been turned in is what we understand. It does not reflect on the CMS website right now, but Vermont in Arizona are in but we understand they turn to the plan fairly recently and they were under a bit of a different scenario. CMS is also issued CMIA letters to almost every state and according to the website or seven states that have not received their letter, but sometimes the date of the letter is a little bit before when Ashley posted on the website - actually posted on the website. And CMIA stands for clarifications and modifications for initial approval but I will refer to them as CMIA letters.

>> And just to be sure everybody understands, this process of transition planning is a very iterative process. We will see a lot of states and we already have seen a lot of states, come up with one plan and go back and update it and make changes and come out with another one. There are multiple opportunities for public comment throughout the process and also just in general, less formal public input. As was said earlier there has been individual program transition plans so if the state had a 1915 (c) up for a new or had have additional changes that individual waiver have been approved and had some transition information and it.

>> And so there are other places to look for state information too. Some of the trends we saw on the early plans, a lot of the plans were very skeletal, not many had a lot of information, and this made it difficult for stakeholders to provide comment or input because we really did not know what the states meant or what they were intending was a statement about we will assess settings. It is like why or how? What is the process?

>> And we recognized states were in the same position of trying to figure out how they were going to do this too and so in the early stages it was trying to figure it out and there was not a lot of information being provided. States also sort of had a different approach to it and some were saying this is a great opportunity to figure out whether or not our programs are providing them what we want them to provide and giving the experience to the participants we think it should.

>> Some other states or approaching it saying what we have to minimally due to comply? It was a pretty stark divide when you were looking at plans to the approach and of course is advocates would prefer a holistic view of saying what is working and what is not working in our system right now? And how do we use this as an opportunity if we have to go ahead and do

this work, how we use it as an opportunity to improve the HCBS program in general?

>> A lot of states were going towards assessment processes the settings that relied on a lot of biased information, and did not have a lot of sources of information. We will talk more about that later. Also some states were very focused on the providers and other states were focused on participants. As advocates who are looking at a program about HCBS in the whole point of the regulation is to focus on the participant experience, we were certainly pushing for greater focus on participants heard

>> Another aspect in the early plans was there is a big difference in how much stakeholders were involved and whether or not states were having ongoing stakeholder involvement and whether or not the people were listed, so that was early. Where are we now?

>> We are seeing some of the same ongoing issues. Certainly the assessment process is a struggle in terms of trying to figure out how states are doing it understand that states are trying to figure out how to do it themselves but there seems to be a lot of issue about how do you do an assessment in a way that provides accurate information and is free from bias as possible? If you're looking at what the participant is supposed to be experiencing the really needs to be a way to get at what the participant thinks of the setting and ensuring the participant has sufficient information about what the regulations are supposed to provide to them so they can answer the question.

>> It is very difficult, for instance, if an assessment says to an individual that do you enjoy sufficient community integration? If a person does not know the level of integration they're supposed to have the level of choice they're supposed to have, they may say that what they have now is fine, but that is not really a true reflection of whether or not the provider is compliant with the regulation. It is important to make sure the any type of assessment process has sufficient information. We'll talk more about that later.

>> A lot of the assessment processes are not a terrifying much to identify settings isolates of that is a problem. We are also seeing a lot of problems with the standards states are using about community integration. Some states are including information in their plans not accurate to what Daschle rule says - what the actual rule says the regulations as the comparator is whether or not the person purchase a painting within HCBS has the same opportunities as someone in the community who does not receive HCBS services.

>> A lot of states are comparing it to other people with disabilities, or you know, people doing the same type of activity, and that is not the correct comparison. And there is also concern about what level of integration states are requiring. There are similar issues with updates to state regulations and policies in terms of whether or not states are looking at the regulations and saying are they compliant with the federal regulations? Do they support the federal regulations?

>> That is a big issue and some are using and correct standards.

Transparency continues to be an issue terms of whether or not states are really communicating with stakeholders about what they are trying to do and what their plan is going to be. As I mentioned before public education and involvement continues to be an important part is something that we often see states are lacking.

>> We really believe that education is critical and making sure there is not a lot of fear and misinformation going on about the rules and changes that are occurring, and also tell people the involved in the process. One of the biggest ones we still see and are particularly concerned about our most state plans do not mention, much of anything at all, about capacity building.

>> In terms of whether or not the state is looking at do they have the right array of settings to meet the needs of the population they have? And to make sure that in the transition period that people will have an opportunity to select a setting among an array of settings that include a non-disability specific setting as the regulations require? That is a big piece and states are not portraying there may be some changes in providers or in the mix of who a certain provider serves, so they may need to encourage the growth of new settings to meet the needs of the population.

>> We also quickly wanted to go over some of what CMS has said in their letters to the state and a lot of the trends are sort of along the same lines of what identified. With compared and read over all the different letters that CMS sent back to the states of these are the main trends we identified from the letters.

>> One of the big ones is they have been very clear, by they I mean CMS, have been very clear that public comment and state response to public comment are very important, they have called out states that do not properly summarize or respond or describe why they do not incorporate certain comments into a state plan. There has also been some problems with an adequate notice that states provided for public comment.

>> It is important that everybody understands, especially as stakeholders, CMS is recognizing this is important and it is really relevant to whether or

not stakeholders are commenting and that states are providing the appropriate opportunity and that states are responding the way they are supposed to respond under the regulations.

>> The other big one is that the plans are often not describing the settings that provide HCBS services and are also not providing a complete list of those settings nor the number of participants that uses those settings. CMS is asking for much more complete information on that front.

>> They did make a note in one or two of the letters that the settings that are owned by participants should not be included in the presumed compliant category. If that setting also offers services to other HCBS participants, so for instance, if a participant owns a home that has other individuals living in it and functions much more like a group residential setting, it should not be considered presumed compliant just because it is owned by the individual and is operating like a group setting.

>> CMS also noted that the standards crosswalk and level of compliance has issues in many states, these are where states are supposed to say what policy rules they are related to HCBS and whether or not they are compliant, a lot of states as I said before are not pointing out whether it supports the HCBS regulations and we as advocates think it is particularly important that any policies or procedures are not just [ Indiscernible ] and they should make sure that for ongoing compliance issues that the policies procedures are fully supportive of the requirements of the regulations and not just general so having something that says residents are assured privacy does not really support the full intent of the rule. If it does not have anything about visitors, and the lockable doors in that type of issue to say this is what is required under the regulation. I am going to turn it over to Dave to talk briefly about the assessment processing issues.

>> Thank you Elizabeth and thank you all for listening. I will say at the start that if I could do a whole webinar on this is what process itself I would and I will try to keep it as short as I cannot focus on feedback. We are right in the middle of a key phase right now - phase right now states are conducting assessments for all settings.

>> Basically the state has to go out and be able to use whatever assessment process it develops to classify settings into groups. So a setting is compliant, compliant with changes, it is potentially subject to heightened scrutiny, if the state decides to do that, or it will be unable to comply.

>> Also the assessment is supposed identify what those changes for any setting that does need to change to become compliant, the assessment is supposed to identify what the changes are.

>> No most states are doing a combination of desk reviews, provider self assessments, this is sort of the dominant methodology using - states are using and some sort of beneficiary surveys or I should say participant surveys to bolster and validate those provider self assessments.

>> But the quality of these tools and the quality of the methodologies being used do vary widely. CMS has been consistent and stressing a couple different points in response to states and I will go through those now. We can open up to more discussion of this in the Q&A if you guys are interested.

>> First, each state must have a comprehensive plan to review every NCBS - HCBS setting and if the state is using a provider self-assessment CMS says the state has have some of his into enforcement all providers are responding and all providers have some mechanism they will have, or that all providers will have to undergo some sort of review. If the provider doesn't respond to a self-assessment there might be an on-site assessment for that provider instead.

>> In other states CMS is also stressed that providers who have multiple sites have to fill out separate assessments for each setting. And also the assessment tools have to evaluate comprehensively every component of the new regulations. This is a challenge and design because states are finding they really need to adapt each tool to accommodate various different types of settings and that is a challenge.

>> Secondly, CMS pointed out flaws that detailed lack of detail on assessment methodology on the statewide transition plans for many states. This included problems with sampling, lack of clarity on how each state would validate the surveys, and since this is so challenging we would have a multipronged approach to assessment so you are trying to get these different perspectives, and CMS has had a lot of questions on how states are going to do that.

>> Also when you get different results from different states, or different survey methodologies, how do you reconcile this different results? When there is a discrepancy what will the state do? Will it trigger for the review or on-site review process? That has not been laid out and a lot of states. But I will say early results from states like Michigan who have been piloting their tools have shown real discrepancies in the responses. This is something we should be expecting to happen if the tools are done properly. It is not

surprising if you think about a provider self-assessment, they may not have a lot of information versus the beneficiary point of view, there will be differences of opinion.

>> We think that is a very important thing. I want to stress it is really difficult to design, test, and conduct a policy process for doing these assessment. A lot of states are falling behind and the big lessons of our is pilot testing is really important involving beneficiaries, providers and other stakeholders at the planning stages is also critical. And having some mechanism so that you are surveying informed participants and informed beneficiaries so people understand the context and the contours of the regulations before their filling out these surveys, I think that is a critical element.

>> Finally, I could go into much more due to on the methodology, which is to talk about reporting, CMS and its response letters noted that states have to sit out the results of the assessment process to CMS this on individual settings, not on aggregate totals.

>> And within other letters they pointed out the assessment results have to be publicly reported and allow for public comment on those setting results. We're not sure exactly what that will look like in every states. Part of this assessment process is of course identify the high end scrutiny sites, the sites that have the effect of isolating individuals.

>> States need almost uniformly need to have not done a good job of how they are going to do that but they will have to identify the settings that will be subject to heightened scrutiny and subject them to public comment. I will leave it at that and turn it back to Elizabeth.

>> Thanks Dave. As he said the assessment process, some states are fairly far along, but that does not mean the state does not have the opportunity to go back a little bit and validate and see where there may be some problems. If they have questions where they do not get information they needed, they can ask supplemental questions, or other organisms to make sure the assessment process is working to getting the information the state needs to identify properly and the classified settings they have, so therefore make sure they know who needs to change and what they need to be looking out for. I think as we have talked about before, the assessment process is so critical in giving the state the lay of the land in terms of how they should plan to move forward in their compliance efforts are what they need to do next.

>> If they don't have the right information from the beginning from the assessment results they are operating on bad Intel brood that is why we are stressing how important that is and that CMS letters to reflect that

importance. On a related note, a lot of the letters site that states do not include much information in their state transition plans about setting remediation plans. Most are not very descriptive, CMS was generally asking for more information about the process and the timelines the states plan to use. Other timelines are particularly important because of the state is not planning for compliance until late in the transition process, that may be setting things up for a poor outcome.

>> If the state does I have time to help providers struggling with compliance either come into compliance, or for the state to have time for dinner by other studies - other settings to expand or do by other settings to ensure the whole system is in compliance and that people who are using HCBS services are using them in the appropriate settings.

>> Some other issues states were asked to adjust as if they had an overly compressed remediation plan, which is duffel an issue or if you are asking providers to change too quickly, it could make it difficult on providers first of all, more importantly, it could mean the changes are not what you want them to be or done in a way that will be long-standing or have a positive impact.

>> We want to make sure the remediation plan allows time for people to change and not have tremendous shock value, shock value is not the right term, but have time to do it in an orderly fashion, especially with the late implementation period that CMS was noting. And the heightened scrutiny process is particularly an issue because states have I defined what they will do to identify settings to get her heightened scrutiny and as a reminder those settings me together heightened scrutiny that have institutional characteristics, but the states they they can overcome that presumption by the HCBS character of the setting is self

>> Of course it is fairly easy to modify the settings on noninstitutional campuses or meet the first three of the four ideas or criteria around what heightened scrutiny is, it is the one about those isolate and are particularly problematic to find, and most will not give more information about how they will identify all the types of settings and need to go through heightened scrutiny. Nor do they set on the process they would use.

>> Some states are saying all we were looking at his location and that is enough. It cannot be just about proximity to other institutional settings. By the very nature they to isolate the individual from the larger community and so you need to identify that is the location is not enough. And as Dave said they have to have heightened scrutiny and have it open for public comment.

>> A lot of states or say our participants are choosing the setting and so that is relevant to the heightened scrutiny position. And at least some of the letters, specifically for Kansas, CMS so the choice is not particularly relevant to the heightened scrutiny process. His head that if an individual chooses to Ryan in the study not compliant by the end of the transition the study can no longer be funded [ Indiscernible-low volume ] .

>> Yes choice is relevant to the regulation, but the setting itself need to be compliant with the regulations, a person can choose to live in an institution but it does not help that facility to be compliant with the regulations itself.

>> And the last big one we identified is a trend was a lot of states did not have much information about beneficiary notice and the protection. So a lot of states were silent on what would happen to participants within HCBS programs that would need to change settings. And if a setting Oort to say were not in compliance and a client had to move or kind of tensions are in place for the individual, when will the planning occur for the individual?

>> Most states do not have a lot of information in their plans about this. One of the big pieces that we have identified is that there may be a change in the mix, I'm sorry, there might be a change in settings in terms of who they provide services to in order for them to reach compliance. And so there may be some sort of changing of where a participant goes for their services or who they use for their services and it may be true that through the person centered planning process people identify that they are not in the most integrated setting appropriate for their needs. So there will be movement through this process even if providers are not shutting down so I think a lot of states are not recognizing that is a factor that will go on.

>> The one that we are particularly focusing on, especially for this presentation, because we think it is very important that states are involving their stakeholders, and that it is really using those who have the information about both the settings and the problems in the plan.

>> We have identified states that are not using multiple sources of information, whether settings assessment or for any type of stakeholder activity they have. Also, issues about transparency and information results, a lot of things are not identifying opportunity for input, it is very typical for stakeholders to know when they will be able to provide input or how if it is not identified in the plan.

>> Some states have clearly said you can offer us input any time, anyway, here is an email address that goes directly to our group or team doing this, please submit feedback at any point, you don't have to wait for a formal comment process. Other states are really trying to limit it to discrete periods

of time and have set that out in their timeline, but not all the states are closely adhering to this timelines, so it is hard for advocates to identify when they should be planning broad input.

>> And as mentioned before the setting for heightened scrutiny and identification and evidence the state will use to overcome the presumption needs to be very public. We talked a little bit about this before, but the big issue of appropriate timing for capacity building and transition, we are very concerned about the states pushing the stores the end of the compliance period and we also know that things don't always go as planned.

>> If you're pushing total compliance in any kind of transition to the end it may be a very brushed period because not everything will have gone the way we want it to, so not only are we pushing to ended on a period of time but to make sure the state is clearly playing for any kind of transitions that are going to happen and providing due process protection.

>> As I said before, we have seen a lot of lack of information about the non-disability specific settings and also that states are not planning for any type of provider changes. And we have seen some states that are saying well, our providers will stay open until the participants that are there find new placement. And we're not sure as a practical matter that will be very realistic for a provider to stay open or for that to be the states plan. We think then is to be a fallback land on the states part because it doesn't seem very practical or realistic to expect providers to stay open while all the individuals who have been participating in the setting find replacements, particularly as the numbers grow low.

>> I will turn it over to Dan to talk a little bit about the state perspective on these issues and what is going on on that front.

>> Hello everybody and thank you for being on the call and thank you for inviting me to speak to you about the state perspective. Elizabeth, Nicole, and Dave have given you so much data. What I want to talk about is broadly, what are the challenges states are facing and what role can advocates play in helping to meet some of his challenges?

>> Let me see if I can successfully move the slide. Number one, the states are looking for a moment of clarity. A lot of what folks on the webinar before me have shared are some points in the rule that are really able to be clearly turned into standards, it is very clear what some of the stuff means. But some of the most important language in the rule, states are challenged by it because it paints a very powerful, aspirational picture about how public funded support should support people to live the life they want to their communities.

>> But much of that language is not easily turned into standard. Terms like it must be integrated in and supports greater access to the greater community, provides opportunities to seek employment, optimizes individual initiative, autonomy and so on. Strong, very good language, difficult to break down into specific requirements. We all know there are differences between advocates, family members, providers, and yes, states about what constitutes being integrated into the community. How optimal does something had to be forcing us to consider optimized and how many opportunities to seek employment need to meet the standard?

>> If you take a look at the mission statements of all the IDD agencies, I should pause for a moment here and mentioned, I worked for the capital - national Association of disabled services, I am with the state agency in my comments are from their perspective we work closely with some of the other associations for the other types of state agencies and so I can talk a little bit about what we have talked about with them.

>> Really should take my comments as speaking from the perspective of the state DD agencies and not necessarily cross all populations. But if you look at their mission statements, you'll see a lot of the language in the rule has been reflected in the mission statement for years. This is the stuff that was that we were doing or have been trying to do for a long time.

>> At this point Sibley sharing the same aspirations is not enough. The reality and running a large and expensive system is you have to be able to manage it to specific standards. Especially where you have the states that are really trying to use of the rule as a catalyst to change the system and drive reform. Obviously, like I said, there are differences of opinions and every stakeholder group about what the system should look like.

>> So when you're encountering resistance being able to point to specific federal expectations and to explain to governors and legislatures what it is you have to do can be away to push through some of the inertia and get to the place you want to get to.

>> I mentioned that we worked with the other associations and we all talk regularly with CMS about how implementation of the rule is going in one of the things we have asked for a lot is how do we transform some of these things into standards. A lot more guidance been coming out and clarity is coming but it is also become very clear to us that through the conversations the public comment process and public participation is that CMS is really prioritizing that as a means to come to some of this clarity. What does that mean?

>> That means it is really an opportunity. Like I said I cannot speak about all the fields and all the different populations that are served through HCBS in the same expertise I can talk about the DD world but in the DD world the system was built by family, advocates, providers who grew up with the system and states in collaboration. Sometimes another collaboration has felt more antagonistic than not but the bottom line is we built a system that in the late 60s pre-lunch everybody was getting publicly funded support was in an institution, a big institution, to now, where we are really focused on community integration, and we have concepts of self-determination and all of these things that have really happened because of that collaboration with families, advocates, self-advocates, providers.

>> This rule has asked the question of every state what does this mean to you and what do we and our state make by integrated and how optimal is good enough for our state. It is an opportunity for us to continue the dialogue and directly address the questions what are the values we want in our system and what does integration mean to us. When we look at that aspirational language, and when I say we I mean any given stakeholder within the state, when we look at that aspirational language what does it mean for our state? States need the stakeholders to be involved in it is not because the states may go off and do something without the stakeholders but it is because the states cannot move the system in any direction if we don't do it with the stakeholders so states need stakeholders to continue as you have been the last 40 years and to be involved in that conversation and to continue to help develop for your state, what your understanding is of what the rule means and what does it mean for your system?

>> As you all know advocates are not all on the same page on how to optimize or help or what this looks like. That even more so means that everybody needs to be engaged as much as possible to make sure that the states are hearing from the broad range of advocates and are able to use that to set the direction in which they are going to move.

>> As an aside, some of my members have mentioned, for example, they want to use of the heightened scrutiny process to have CMS weigh-in on some of the settings you may actually want to close.

>> I think that is a risky proposition because again, we don't know exactly what the standards are, exactly how clear they are and there are some that are clear and some that are not, so we want to make sure that the advocate voice and stakeholder voice are part of determining that as these transition plans go through several iterations, we want to make sure the stakeholders are really involved in the direction.

>> I need to discipline myself to not read the chat box while I am speaking. The next thing that has been challenging for states is the timeframe. The timeframe called on states to have a statewide transition plan, depending on when their first renewal of a waiver happened or amendment. It called on them to the statewide transition plan sometimes within three months of the publishing of the rule, but everybody essentially had to have one within the year.

>> That was a real challenge especially because we are still seeing guidance coming from CMS, even in the last couple of months, we have seen a few webinars and conference calls around how to write a transition plan and what should be in a transition plan. That stuff is extremely helpful but that clarity did not necessarily exist early on.

>> Furthermore, a lot of this, building these transition plans some states have upwards of well more than 2000 settings that need to be assessed. We actually had some members report to CMS a were having trouble engaging stakeholders in the process of building the transition plan because they had to have it published so quickly and they had such a short timeline to get it published in order for the stakeholders to give their feedback.

>> So again, this is the fact that states need stakeholders at the table so that during the process of building that transition plan they have them. One of the issues that advocates should be aware of is the need to meet the deadline may drive the scope of what the state is trying to do.

>> To be quite frank, this created a dilemma for states in determining their approach, this tight timeline of needing to make pretty significant systems change in some states and have it done by 2019. And really it creates a dilemma were states had to pick one of two options. Do we figure out what to do in the time allotted or do we figure out what we need to do to get our system to truly meet the full meaning of the language in rule?

>> If you think it will take you 10 years to get there than maybe you will do something a little less aggressive. A couple of states took the approach of just putting timelines and deadlines in their transition plan that goes beyond 2019, we will see how that works out with CMS. States really need stakeholders, again this is my message over and over, states need stakeholders at the table to figure out what we need to do and figure out how to we need to do it.

>> Even the states who are worst at this stuff, there are some providers and entities in the state doing really good stuff and it is the stakeholders

that can help the state learn from those folks and build some of his activities into their system.

>> And I just want to talk about one more thing, and then Elizabeth and Nicole have both talk about public input and I will skip over that except to say it is ongoing and it will not be every iteration of your transition plan, it will be every substantial waiver amendment, every new waiver, every new I, J, or K, so you're being called upon to be consistently engaged in that is incredibly important for states.

>> There is one piece of information that as comprehensive as they were, Elizabeth and Dave left it to me, that is to talk about once will the states have to address some of these real challenges about the direction in their system. I included the language and it is from a CMS FAQ and I will not read the language as I'm over time.

>> I will tell you that CMS is said you can use your transition plan to create one standard that meets the rule, it cannot be beneath the level of the federal rule, but where you say that things we have in our system that we think meet the federal rule, we are going to leave in the system, but we are going to suspend new provider approval, so we will not close it down and move folks out, so again it has to meet the rule. It does not mean that you can keep a bunch of stuff within your HCBS system that doesn't meet federal standards. There is a higher standard or different standard the permits new or existing models of service. Those would be the ongoing standard for the states and new admissions and new providers will need to meet the standards.

>> One of the real challenges for states is this rule does not establish between populations, it is run Wirral - one rule for all populations and their different social norms for different populations as there should be, we should have a really different since or what it means for child to be in the community and in another sense for what it means to be a 30-year-old with down syndrome for example to be in the community, and then there are different social norms and expectations.

>> We talked about how the space to be compared to people who are not receiving Medicaid services. Retired people not sitting Medicaid services often choose to live in an area, together with others, and that is the type of environment that many people in other populations in many people who are working age adults, would not choose to do.

>> And so this tiered standard can help states address that issue and to look at setting standards for some populations or in certain waivers that would be different from standards of other waivers, but again, they all have

to meet the federal standard. We are talking about the ability to create a standard for part of your waiver or part of a waiver that is beyond the standards set by the HCBS rule.

>> As long as it is in your transition plan, you cannot do it outside of, but as long as it is within you can continue on until 2019. Advocates should be aware of this because it is the tools that states can use in a way to address some of the differences causing challenges for states. And so that is what I want to talk about. I will turn things back over to Nicole.

>> Hello everyone, glad to be back, I will power through this so we have time for questions. We wanted to go over some resources available, and has really focused, very importantly, that this is a great opportunity to use the HCBS [ Indiscernible-speaker too distant from microphone ].

Stakeholders as we discussed must have a place at the table and must be armed with the right information.

>> We are looking at rules and regulations [ Indiscernible-muffled speaker ] [ Indiscernible-speaker too distant from microphone ] I need to turn myself up again. I'm sorry. It is important to know that CMS is looking at public comments, the move towards system change requires a lot of rule changes, changes in licensing, and that sort of thing.

>> Stakeholders must be part of that conversation and it is very important that you look at the state plan. I am sorry, it is very important that you look at your state plans as you move forward. I just want to share some resources, [hcbsadvocacy.org](http://hcbsadvocacy.org) is an extremely helpful website all of us are working on, we update it very regularly with information on what is going on in particular states.

>> As mentioned you can find all the fact sheets and questions and answers, both the once provided by CMS as well as once we are working on with our internal organizations, which is a collaboration of a bunch of different organizations we are currently working on an updated FAQ on the HCBS regulations as well as and advocacy toolkit on how folks can work together.

>> At this point I will turn it back over to Joe to go through the questions.

>> Great. Thank you for great presentations. We have gotten a lot of questions and we will try to get to as many as we can, keep submitting them. Let me start off with some basic ones that just sort of clarify some things, some people were asking for the link to the CMS website where they can find the plans and everything.

>> Of course, that URL is really long, but I am pretty sure in the materials that we will send around after the meeting, you will get the PowerPoint.

That will have the Livelink that will go directly to that site. You may also go to that address on the previous slide, [hcbadvocacy.org](http://hcbadvocacy.org), and that will take you to the brightly.

>> Another question that just came in to clarify things, early on there was a reference to CMIA letters and a lot of people were asking what the heck is CMIA? To be honest I had to Google it and it stands for clarifications and/or obligations required for initial approval. I learned something new. Basically that is response letter from CMS about the transition plans that been submitted. Let's get to the questions and I will start out.

>> Joe question mark this is Dave. I wanted to jump in for a second. I wanted to point out I always called in the transition plan response letters because it makes more sense but they are available for each state on the CMS website on the HCBS state plan website. And also we have summaries of those letters by state on the [hcbadvocacy.org](http://hcbadvocacy.org) website so if you want to find your state's response those are both good places to find them.

>> Yes, great, that website [hcbadvocacy.org](http://hcbadvocacy.org) is the go to place for a lot of resources, has off to AUCD, they try to keep it updated with all the information and toolkits and things for advocates. A couple of these questions have to do with stakeholder engagement. And so I kind of wanted to start with those because that is the main topic of this webinar. You know, the concern that a lot of the states are not educating stakeholders, particularly in plain language, and you know I was thinking also about self advocates with developmental disabilities or intellectual disabilities. The question is really what is the responsibility of the state to educate stakeholders and use plain language? I wanted to see if anybody had any thoughts or answers to that

>> This is Elizabeth. There are some states that have created, or at least tried to create accessible versions or more accessible versions of the straight transition plan and created materials on it. I know that North Carolina did that and some of the other states are creating sort of right information as part of their education plan. There are attend at making it accessible but of course there are always obligations under the state 88 to provide reasonable accommodation if somebody needs the plan to be accessible to them and to do something to address that.

>> This is Dan. I want to say that CMS, Center for Medicaid and Medicare services, have also been very aware and pushed back on states and make sure that they are not only providing information, you know, pushing them to attempt to provide information in plain language, but also make sure they

are providing it in ways that are generally accessible to all the stakeholders. If estate has put - if a state has put some sort of public comment and in a certain place but it is not easily accessible online CMS pushback is that it will not meet your public comment possibilities so CMS is taking seriously the need for states to put on this information in a way that everybody can get a hold of. That does not mean it is going well in every state and so states really need to hear from stakeholders if it is not going well so they absolutely do have an obligation to do it successfully.

>> Good. This is one I think you all can provide some advice on. What should you really do if you are concerned the state is not listening, or not including things that have been brought to their attention or misrepresenting things? What sort of advice do you have for advocates in that situation? Who should they contact and how can they express concerns?

>> This is Nicole and CMS is indicated they are looking very closely at public comments. Sometimes they know that those things are submitted and they going to the ether. What they really are looking at those. So contacting CMS directly, so we have seen issues and states were certain settings are not accounted for and that is an easy example, and just making sure. And that is why it is so important again to have folks on the ground looking at these plans and making sure that these states are accounting for all settings.

>> I would add that the first point of information is always to the state but if the state in it's summary of comments has misrepresented a comment, they are supposed to summarize the comments and respond to, if they have not included something really relevant in their summary from your comments, it is relatively easy to write a simple cover letter to CMS with your comments and say this is what they do not pay attention to and this is a concern.

>> I would not say go to CMS with all of your concerns now. Try with your state first be the appropriate step to advocacy.

>> Here is a question may be for Dave or Dan. This is a tough one. In order to do a good assessment, it costs money, there are implementation costs for the assessment. I think the person asked the question was concerned it had to come out of the state Ajit. - Out of the state budget. I was curious if you have seen or states are doing pretty robust assessments are looking for other resources, how are they creatively addressing that to do a really good assessment, which is what I think we all want. Any thoughts?

>> I will start by acknowledging that is a real difficulty, it is expensive, and it is hard to do an accurate assessment. That being said, you know, it is something the states do have to do. There has been another question I saw which is what is a model state plan or what is a model approach? It has really been difficult for us looking at all the state plans to single out a state and say hey, go do it like Minnesota.

>> Because every plan has strengths and weaknesses. There are great places and a lot of people interested in sharing information. If you're looking at the assessment process I know Michigan has hired their state USED to help implement that assessment process and design it. I think that is a good place to go for some ideas.

>> Maybe Dan has other ideas on how things are coming from the state perspective, it would be nice to have a clear funding source for doing these assessments but that has not materialized.

>> I wish I had an answer beyond what Dave just said. This is one of the number one things that my members are challenged by, and I assume this is true of the other HCBS operating agencies as well. The reason is, that said, the states have an amazing number of sites to visit and they do not have a whole lot of administrative staff at this point.

>> So trying to figure out how you make an accurate assessment of every single site, especially when you're looking at needing to look at some sites that might be a single person site, it might have one or two people, it is a colossal task.

>> That is one of the reasons that when I was talking I was trained emphasize the need or stakeholder engagement. Just as the DD system has always moved forward because of the work of stakeholders, this is really going to take stakeholder engagement to make it possible for states to understand all the different settings that they need to take a look at.

>> And to add onto that, for some things like setting design or assessment tool designed and sampling process, some of those things that are stakeholders that are really interested and engaged in that process and in some of the nuts and bolts. Having a robust stakeholder process could help estate not have to expend all of the resources by itself.

>> I do want to add quickly there are states being created about leveraging information sources they already have. You know, educating the licensor departments about what regulations mean and asking those departments to provide information about what could potentially be problematic settings and kind of given flags already, talking to ombudsman or protection advocacy organizations, I didn't find this sources of information - identifying

those sources of information that can provide direct feedback to narrow the field of it on the states work.

>> I have another couple of questions but I wanted to give a heads up to presenters, we are running short on time. If you saw a question that you are burning to answer, go back and pull that out. I will ask that this one, which is around the person centered planning requirements, the question was around CMS guidance on this. I thought they did put out a lot of guidance and toolkits around that, is there more coming and are all of those on [hcbadvocacy.org](http://hcbadvocacy.org)? I wanted to know the update or status on that.

>> I will try to answer this. Person centered planning is already in effect and the regulations are supposed to be currently being followed and are not part of the five-year transition plan. That being said there is old information that CMS gave a while ago about person centered planning and managed long-term services supports. The preamble to the regulation actually have a lot of information about what they are expecting person centered planning to look like.

>> I would address a question that I saw about limiting person centered planning being used to limit freedom of choice and the whole point of these regular from person centered planning is to do the exact opposite. There is a lot of language and the like - in the regulations about making sure there is choice and making sure there is recognition that a person has some freedoms and abilities to take some risks in the process. The changes to the person centered planning process should make it much better and more focused on what the individual wants, and less sort of perhaps the more provider center process the planning may have been in the past or what is available to process. [ Indiscernible-low volume ]

>> Just to go back to the presenters, were there any questions you saw that came in you about to address before we close?

>> The only one I didn't want to address the someone asked whether or not this means that certain settings will have to close. I wanted to make sure that everybody knows that while there are mechanisms for settings together heightened scrutiny and mechanisms for settings to come into compliance, there is time for all that happen.

>> There could be settings that can overcome all of the characteristics, whether or not setting wants to do that is a different question. Is it possible? If the settings want to do that? That is an open question. There may be some that just cannot overcome.

>> We had a number of questions around rural communities and the lack of capacity in those places. And I think those are important concerns. And that

is one of the reasons why is advocates we have been trying to stress what is the plan for building capacity in these places or there are not any good options? The regulations say that everyone is supposed to have an array of options including a disability specific setting ultimately the how will the state be addressing that long-term? It is a challenge.

>> I think that is one of the reasons that we bring up that tiered standard, thinking about what is going into new construction and what our vision is going forward for those places that we know there are difficulties. In terms of the specific setting, if the setting is on the grounds or campus of an institution, it would have to go through a heightened scrutiny process and that would really depend on what kind of evidence the setting can put forward and the state can that forward about that setting that shows it is doing enough to integrate those people and participants and satisfy all the other requirements that are part of the rule. That is dependent on the characteristics of that setting and it is hard for us to give an answer. I would say at least in the work they have done so far CMS has set a high bar for what needs to be included as evidence for heightened scrutinies.

>> Any other closing thoughts or comments from the presenters?

>> [ Silence ]

>> I do want to thank you presenters and everyone for attending and. I think the take away messages this is a long process and everyone has to say involved, particularly advocates at the state level, this is not going to happen overnight and as things rollout we will continue to keep folks updated. The real work is that the state level.

>> Just in closing, again, everyone will get a copy of the PowerPoint and the recording, probably within the hour. If you want to access any of our previous webinars, the disability and aging collaborative webinars, they are all available on our website, the address is there and we have done great webinars in the past around managed-care and home and community-based quality measures and rebalancing.

>> We are planning some exciting webinars in the works. Stay tuned for those in the near future. And again, thank you everyone for attending and. Have a good weekend.

>> [ Event concluded ]