

5/17/23

HCBS Meeting

>> Marcia Gordon: Okay, we're going to go ahead and get started. It looks like we've got close to 300 folks in here now. So we will go ahead and get started. Hello everyone, good afternoon. My name is Jill Jacobs. I'm the Commissioner of the Administration on Disabilities. I will describe myself briefly. I am a middle-aged white lady with brown hair, pulled back today. I'm wearing glasses with red frames, a brown sweater, and I don't know a tan top. And I'm in my office today in DC. And behind me is an American flag and another flag I always forget what it is. I think it HHS. I should have to figure that out sometime. That one is blue and yellow. So we're going to talk today about what we've been talking a lot about home and community-based services. This is the fifth in the Administration on Community Living's webinar series on the role of stakeholders, all of you, in entering high quality in home and community-based services. So in this session, we are going to dive into the Medicaid Waiver Application, by that we mean the state Medicaid Waiver Application. And we're going to focus on the section related to participant rights. So a little bit of logistics. Participants will be muted during the webinar. You can use the chat feature in Zoom to post questions and communicate with the hosts, the chat window is there at the bottom. Toward the end of the webinar, our speakers will have an opportunity to respond to questions that have been entered into the chat. The webinar will be captioned, live captioned in English. Live English captions can be accessed by clicking on the CC button at the bottom of your Zoom screen. If you hover your mouse over the CC button there's a little up caret you press that up arrow. You can click on caption arrow can click on full caption. This live webinar includes an evaluation poll at the end of the session. So if you hang on to the end, there will be a very, very brief, it won't take a long time, brief evaluation, we hope you fill that out because it helps you do better. Each time we get an evaluation we know what we need to do better the next time. Our agenda today, the Medicaid Waiver Application, an overview of the med -- the state Medicaid Waiver Application. Participant rights which is Appendix F of the application. The question and answer session and closing comments and evaluation poll. Next we will -- oops -- so next we're going to talk about, I'll going to talk about why the waiver application is important. States describe who and how many people they will serve in their waiver application. So when they -- can you do the next slide, please. Thank you? So when a state applies to do their waiver, they have to describe to CMS who and how many people they're going to serve in that waiver, what services they will provide, and how much. What protections are in place, whether people can self direct and family members can be paid, how they will follow the home and community-based services rule, and when CMS approves the application, the state must implement it as approved. Only what is in the waiver can be provided. So states can't say we want to provide something that doesn't exist. And now I will turn it over to, I think Nancy.

>> Nancy Thaler: Is my video on? Hi everybody. Erin, would you like to walk through some of the other points on the slide before we get going?

>> Erin: Did you want me to do everybody's bios and everything?

>> And the logistics, yeah. Before I launch into this.

>> Jill ran over the logistics about, put your comments in the chat and hopefully we'll have a Q&A session at the end where we'll be able to get to some of your comments. So let me just introduce all of our speakers for today. First we have Nancy Thaler who you just saw on camera. Who you just saw on camera. Following eight years working as a community provider developing community services for children and adults with intellectual disabilities, Ms. Thaler joined Pennsylvania state government in 1987 and served as the Deputy Secretary for the Office of Developmental Programs from 1993-2003. Ms. Thaler served as the Director of Quality Improvement for the HHS Center for Medicare and Medicaid Services (CMS) from 2003-2006 and was responsible for developing the state application for 1915 (c) HCBS Waiver Programs. Ms. Thaler was appointed Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in 2007, serving in that role until 2015 when she returned to serve as Pennsylvania's Deputy Secretary of the Office of Developmental Programs until 2018.

Ms. Thaler is currently Senior Policy Advisor to the Administration for Community Living. She has a Bachelor of Arts and an honorary Doctorate from College Misericordia, and a Master of Human Organization Science/Public Administration from Villanova University.

Ms. Thaler and her husband are the parents of an adult son with developmental disabilities.

Next I'd like to introduce Jill Jacobs who was speaking earlier in this webinar. Jill Jacobs was appointed to serve as the Commissioner of ACL's Administration on Disabilities on Feb. 14, 2022. Ms. Jacobs has more than two decades of professional experience managing disability services organizations, analyzing policy, and working toward improved health and disability programs and services at local, state, and federal levels.

She also has been an active grassroots organizer, leading campaigns to depict President Franklin D. Roosevelt seated in his wheelchair in the national monument in Washington, D.C. and to ensure the inclusion of disabled children in schools and organizing disaster response efforts for people with disabilities following Hurricanes Harvey and Maria, to name just a few of her accomplishments.

Next I'd like to introduce Elizabeth Edwards. Elizabeth Edwards is a senior attorney in the National Health Law Programs North Carolina offices. In addition to working with the National Health Law Programs litigation team to advance the health rights of low income and underserved individuals, her work includes policy advocacy and legal education. Ms. Edwards joined the National Health Law Program after five years with Disability Rights North Carolina, where she was the Medicaid Act, the Americans with Disabilities Act act, and public policy to ensure equal access and community integration for individuals and groups along with other ADA issues such as voting rights and accessibility. A graduate of the law school at UNC Chapel Hill, she obtained her bachelors in environmental science and public policy from Duke University. Despite the law degree she remains an ardent Duke fan. Ms. Edwards is from rural North Carolina and often returns to play in the country and get out to the area greenways as parks.

Last but not least I would like to introduce Elizabeth Priaulx, Senior Disability Legal Specialist at the National Disability Rights Network.

Elizabeth Priaulx provides assistance to P&As related to community integration, with a focus on Medicaid litigation and the implementation of the Olmstead v. L.C. Supreme Court Decision. Additionally, she is responsible for the NDRN initiative to support and encourage P&A advocacy on behalf of senior citizens with disabilities.

Ms. Priaulx began working formally as a disability advocate in 1986, at United Cerebral Palsy Associations and also worked as a researcher at the U.S. Government Accountability Office. She has served as Vice-Chair on the Board of Directors of both the Endependence Center of Northern Virginia and the Virginia Office for Protection and Advocacy. She received a B.A. from Emory University and a J.D. from the Washington College of Law at American University in Washington, DC. Those are our speakers for today. And I'm going to turn it back over to Nancy Thaler.

>> Nancy Thaler: Okay. Thank you, Erin. We'll get started here. You won't hear Jill's voice much but Jill is always on these calls and introduces them because she's really the one behind all of the efforts to increase stakeholder engagement, the webinars, much of the work that our national network is doing, as you know in her resume this is pretty close to her heart. So going to the waiver application, great -- looking at what we have up. So this is I think number 5 in our series. As we walk through the waiver application so people understand what it is and how to use it to get your needs met as the title says. And just to be clear that keep going, next slide, right. This is about explicitly the 1915(c) waiver applications that we know is home and community-based services. But there are other ones. Some states have a 1915 waiver that's just sort of a global waiver. There's 1915 i, 1915j, there are other home and community-based services some of which mirror the HCBS Letter C authority. But when we show you displays of it, it is explicitly the 1915(c). Next. Slide. So this is F. This is the slide always used to show all of the appendices. This waiver application is really a document that's made of predominantly appendices, each for a specific area. We skipped A and B. They're very -- they're about the bureaucracy, how a state runs its bureaucracy and eligibility is fairly complex, a lot of options that states have to pick. But we did one on participant services, person-centered plans, person-centered direction and now we're at participant rights. For this one I asked for two guest speakers to do this. Because -- next slide -- because this Appendix to the application only has one thing that's required. It's every state and Medicaid statute has to have a fair hearing. You might have noticed the note to provide fair hearing that means going in front of someone who serves in a hearing officer role, it's fairly formal. So, what states do to make this a little more user friendly is sometimes they have dispute resolution processes. And they also grievance system, not all states have both, rarely do states have both. Either of these two are required by CMS they're going to walk through the sections of the waiver application with advisories. I'm going to hand it first to Elizabeth Priaulx. And who is going to take the next slide. Elizabeth Priaulx: My name is Elizabeth Priaulx, I'll start out by saying that I am a white woman with glasses middle-aged. And I also wanted to -- because I didn't explain much in my bio, I wanted

to let you know that the way I attain this experience is by working at the National Disability Rights Network. It's the association for the federally-funded protection and advocacy agencies. And the PNAs are receive funding from the federal government to provide legal assistance to people with disabilities who have been discriminated against on the basis of disability and primarily, when it comes to abuse and neglect in institutions or the community, and failure of the government to provide services under programs like Medicaid and other federal programs. And the reason I think it's important to say that is if you haven't heard of the prevention and advocacy agency, there is one in every state and territory. And if you are having a legal issue like this, you are welcome to call them. They do have priority areas they're not able to take every area that someone calls into. So know that. Nancy already explained what Appendix F is, I want to provide a little bit more background on why we need participant rights so badly and why the Medicaid Act provides for this. It's because in the Medicaid Act, the Congress was very clear, they mandated certain services that had to be provided and certain services that were optional for the states to take on. But what they didn't do is talk about what is the minimum level of these required services? Instead, they left it up to the state and they gave them certain guidelines. They said the states are required to provide reasonable standards that are comparable for all disability groups. And then by regulation, they took a stab at trying to provide a little more information about what reasonable standards are. And they said, reasonable standards have to provide enough services in sufficient amount duration and skill to achieve their purpose. They also said that services had to be provided with reasonable promptness, comparable to other groups. So the reason I go through this is not because, well, I think that you already received some information about this when you were on the earlier webinar about Medicaid services. But it bears repeating because it explains why the Medicaid Act offers an automatic right to a fair hearing. And that's because there is always going to be tension between the provider who maybe has a financial incentive, or another type of incentive to deny services and you, the individual who needs the services. And so, that is why fair hearings are so important. Now I'll get into what we mean by this. As Nancy said, whether you're a fee-for-service or managed care you have a right to a fair hearing. It's actually a constitutional right. And it cannot be waived just by a state law for example. Then you also had an optional right for dispute resolution and a grievance complaint system. And Elizabeth Edwards, who will speak after me is going to go into more detail about what the programs are. But it's important to know that this is optional because, you as an advocate are going to be lacking for ways which when you review a waiver you can encourage the state to do things like require, provide a dispute resolution, or a grievance complaint system. There are pros and cons to each. Next slide, please. So, again we want to say that there are different requirements for managed care and for fee-for-service. We are primarily focusing on free for service, which basically says you have to have a State Fair hearing ability. In managed care plans, like Nancy was saying, there were regulations that were published and they provide more specifics on what managed care is by, and in that circumstance, a grievance, a requirement to go through an informal appeal is required. There are pros and cons to that for sure. Okay. Next slide, please. So this is what it's going to look like on the waiver. You can see that it's easy to miss this section. It's important to read the small print. Okay. Go ahead to slide 12. So what are the fair hearing triggers? In other words, when can a participant request a fair hearing, that's when services are denied, suspended, reduced or terminated. The good thing that's pretty darn broad, denied.

Suspended, reduced or terminated. We are not talking about eligibility here. We're strictly talking about services for individuals who have already been found eligible. So this includes termination from a waiver and if the waiver is self directed services, that can include termination from involuntary termination of self-directed services. The reason that we put it here is because there have been cases that have challenged and said, you know, my services have been suspended or reduced, and this meant that I cannot follow the self-directed services that I need. And that is not always going to be found as something that can trigger a fair hearing. So just be aware of that. Oh and what you are also going to be able to request a fair hearing for in addition to services denied, suspended, reduced or terminated asked for the services that are not provided with reasonable promptness. And we'll go into a little bit more about that. But basically, you can make the argument of what services, basically 90 days. But you can also maybe the argument in course about what is reasonable for your needs and why you are at the hearing. So, another thing that triggers a fair hearing is if the fate was not providing a choice of home and community-based services as an alternative to institutional care. That was actually written right into the participant rights section. So that is key. And it's something that you might not have realized that states are required to do. Then it's also denying an individual the services or choice of provider choice. And this has a few caveats. It's also called any willing provider is sometimes how people refer to this provider and their choice. So they have to be a provider approved by Medicaid. And they have to be willing to provide you the service. So it's not that you can just take any provider and they have to offer it. So again, also services denied suspended, reduced or terminated. The other thing that can trigger a fair hearing and something that you should know about fair hearing requirements are that they have timelines for when you have to request a fair hearing, when you can request an expedited fair hearing. There are other very good things like you have the ability to review your full case file prior to the hearing. So you can't just be given information the day you walk in. And the information provided to you during the hearing has to be in your language of choice, and accessible to people with disabilities. So, an interpreter provided, you are required to go to a hearing in an inaccessible location. If they say the hearing must be provided virtually, if you think that a virtual hearing is going to disadvantage you as a result of your disability, you have the right to request that the hearing be available to the person. Or vice versa, if you really need a hearing virtually, that could be considered a reasonable modification to ensure accessibility. You also have a right to an expedited review. So, an expedited review would mean you have to show and prove that if you weren't able to get a hearing faster than say the three months out that they're requesting, that it would disadvantage your health, your life, and/or it would lead to a reduction in your ability, let's see here, I want to get it exactly right. Your health, your life and it would lead to a reduction in your functioning. So next slide, please. So here are the criteria for the fair hearing. When an individual first becomes -- gets on to the waiver, the waiver notice must tell people that they have a right to a fair hearing process if services are denied, reduced, terminated or not provided. That doesn't mean that's the only time that you have. Once a service is denied or suspended they have to get notified you of your right to a fair hearing. And there are specific requirements the notice must provide. And this is an area where states notoriously violate. So you should know this and you might want to as an advocate, as the waiver is being developed, suggest that maybe there is a template for a notice so that you can ensure that it really meets these requirements. Okay. So the notice must include how it will be

provided, over the phone, mail, that sort of thing. It can be provided -- it can't be provided over the phone, sorry. The entities or entity that's responsible for issuing the notice and the assistant, in any case, that will be provided to the person that's pursuing the fair hearing. Remember we talked about in the language of your choice and have reasonable accommodations that have to be made. So next slide, please. Here is more. I think I already mentioned what's called aid paid pending. In general, you have, you know, a reasonable time period after you're notified that the service is denied. They are required to give you a reasonable time period to request a hearing. However, if you want to make sure that the services will continue during the period that your case is appealed, you must request within ten days of the notice that you received for what's called continued benefits or aid paid pending. And there are some circumstances where this is not required, which basically goes also to one of the things that I mentioned about, I forgot the mention about your right to a fair hearing is, you don't have a right to a fair hearing if the denial is a result of a change in Federal or State law that would be the federal law or the state says we're no longer providing this service to this group of individuals with disabilities. If it's the entire group and it is a change in the statute, you would not be able to go to a fair hearing for that. However, if you believe that you don't -- you are not in that group for example that was in the statute, you could appeal for that. But hopefully you will understand the difference. And regarding aid paid pending, again, you have to request it within 10-days of receiving the notice. However, one of the reasons why it's so important to know the requirements in the notice where to go to an attorney, is that, if you find that the notice was inadequate and didn't provide all the things required, then you can still perhaps have a chance to request to continue benefits. And they must specify where the notice of adverse actions are kept, and, the opportunity to request a fair hearing is kept. Could you go back to slide 13? I don't think I properly reviewed what I meant to say about the requirements for the fair hearing. Maybe that is going to be gone over in another area by Elizabeth. But what I wanted to say is, one of the things that's key is the state has to give you at least ten days advance notice before they reduce or terminate the service that you requested. So that is key as far as this requirement that you have, if you want to request aid spending benefits you have ten days some they have to give you ten days before they terminate the benefits. And you have to request the benefits to continue within those ten days. And the notice has to make clear that you have a right to request a hearing or to continue benefits. I'm now going to turn it over to Elizabeth Edwards to talk about some of the ways in which these requirements are not meant and some of the opportunities for advocacy.

>> Elizabeth Edwards: Thanks, Elizabeth. So I see some questions in the chat or in the Q&A already about sort of differences between fair hearing and grievances and appeals. And hopefully this section will help us figure out or parse out where all those different procedures lie. But it is very confusing. Especially if your state has managed care. So, I just wanted to quickly go over some of the things that are missing in the 1915(c) waiver application and the review process, when we're talking about what the state has to tell CMS. So sometimes there's a lot of interplay between you know what, a state has on paper about promising to offer a fair hearings and due process when a service is terminated, reduced or denied. But actually what happens around requests for services and denials of services especially in the person-centered planning process can really impact access to a hearing. So for example, what a person maybe offered

what, are you told about what you can and cannot request in terms of services during the person centered planning process? Sometimes that process can actually function to deny a person without necessarily allowing them to realize they have been denied. We'll talk about some of those examples in a few minutes. Also this commonly occurs when states use budgets processing, where they assign a person a budget based on an assessment of need, and then they may discourage people from asking for services based on some strict interpretations of budgeting. And so sometimes when a state has a waiver process, yes, we offer due process and notice and rate to a fair hearing in section F it seems very kind of basic in a lot of ways and doesn't really capture some of these areas in which there may be problems with how a person accesses services. And this was an area where there's opportunity for advocacy to sort of really force the state to lay out what protections are in place for people when they are requesting services in the person centered planning process when they are denied services, and what does that lack like? And how are notice and due process rights trickered in some of those processes. What does that look like? I refer to this as discouragement. But it doesn't really -- the waiver application doesn't require a state to say how we are protecting against discouragement. By discouragement I some of the features like o you can only request X amount of services regardless if you only need more. Only request this because that's what we'll approve. Or some different ways in which people are discouraged from asking for services can sometimes be a violation of notice and fair hearing rights. Around if the state -- if an advocate can help push a state to include some protections against discouragement in the waiver application in the sections, it can really be helpful when people are trying to raise their hand and say something is wrong. Also, there is a requirement in the section F 1 to talk about what education is provided to individuals in terms of, you know, when and how a person is informed of their fair hearing rights. But this doesn't necessarily provide a lot of information about how a person is to understand those fair hearing rights. It can be pretty complicated it seems fairly straightforward to say, oh, you just have the right to a fair hearing when your services have been denied. What does that denial look like? When you go through these other processes, grievances and complaints versus when you go to fair hearing and some differences between when it's a fair hearing or a grievance or complaint. There could be more information in the waiver to sort of set those things out so there's more clarity, to make sure that people have more education and there's education at the time of a fair hearing right is triggered. Also, assistance to individuals in the waiver application and the review of the application by CMS in CMS. In every state there's a protection and advocacy system. That I may not always be able to provide services. But it is technically available as a resource for people. And I think arguably that information should be included in the application about, you know, what type of information is a person provided in the fair hearing process? So those are just some things I will say, there's room for advocacy, in the application process when a waiver is up for a -- a new waiver opens up for an amendment. Next slide, please. So, Elizabeth will largely -- Elizabeth and Elizabeth Prialux went over the fair hearing process. So next we'll talk about Appendix F 2 where there are additional dispute resolution processes. I will admit this is where it gets a little bit confusing, especially between F 2 and F 3 which we'll talk about in a minute. But as Elizabeth Prialux mentioned earlier, Appendix F 1 about the fair hearing process is a required section. But F 2 which is about additional dispute resolution processes is optional. So some states operate in additional dispute resolution processes outside of their fair hearing

process. It's important to note that this process cannot be required to be used by an individual as a prerequisite to the fair hearing process or to operate in place of it. And we'll go over a few of those requirements in just a minute. But this on the slide is just the section of the waiver that you would see and how you the state has filled it out in your particular waiver. Next slide, please. So as I mentioned, what you would see many the waiver on an additional dispute resolution process is, how the state defines the dispute mechanism and how it describes what type of disputes can be addressed including any processes and timelines. It has to which clear in the section that it cannot replace a fair hearing basically, or, force the person to go through this process before a fair hearing. I did want to note as Elizabeth Prialx mentioned earlier, when you're in management care you are required to do the informal appeal process to the managed care entity. But that is different from this process, although the state made describe that process in the section of the waiver. I know that's kind of confusing, but hopefully during the Q&A which we reserved time for we can explain a little bit better. Basically in you're in fee-for-service for your waiver services, you would go straight, you can go have I got to a fair hearing, this dispute resolution process cannot impede it. Under managed care, if the state uses the managed care grievance process as part of it's dispute resolution process, you may have to go through the informal, that kind of informal hearing before you get to a fair hearing. I hope that makes sense. But we can answer more questions later. Next slide. Sorry, I forgot I actually had a slide up for this. But as I said similar names can really create confusion because managed care, under the managed care regulations it is caused a grievance. You would -- it is called a grievance, you would often hear that term from a state's alternative dispute resolution as well. We'll try to parse that out a little bit later. Next slide. To make things even more confusing if we're not confused enough yet, Appendix F 3 allows a state to identify an additional state grievance or complaint system. The trick here is that, this part of the waiver is really supposed to cover is more issues with a person being dissatisfied with their services or seek resolution of problems and issues with services that are either being received or that have been authorized. Typically, this type of state grievance or complaint system under F 3 is more about sort of satisfaction with services as opposed to getting or not getting service that you want or have already been approved for. So this could be issues with providers, or, a person sort of being dissatisfied with their experience or not being treated well by a provider, maybe even your care manager that type of thing. This is where that type of grievance or complaint would go rather than as Elizabeth Prialx explained a fair hearing is more about when your services are denied or terminated. Again, this isn't another optional thing for a state to fill out. And again, it's still not supposed to intermine access to fair hearing. Next slide. One of the things that is important here is that sometimes these are more local and provider-based complaint systems. But the state is still supposed to describe if they have this type of process, the types of complaints that can be addressed, the processes and the timelines, and again that it can't be used to limit access to the right to fair hearing. Like I said, these are much more supposed to be satisfaction type complaints. Or issues with how services are provided as opposed to whether services are provided or not. The next slide, please. So I wanted to spend a little bit of time walking through a North Carolina example that hopefully will sort of just give you more information about what this looks like in practice, and also, some of the ways in which a person can be discouraged from services that should be triggering the fair hearing process as opposed to triggering either the complaint process or the alternative dispute resolution process. So,

several years ago, probably almost ten years ago at this point, a lawsuit was brought in North Carolina around the waiver for people with intellectual and developmental disabilities in North Carolina at the time, this waiver was operated under concurrent 1915B waiver so it was operated by a managed care plan. These managed care plans were regional in North Carolina. And what happened was, people, the managed care plan started using a new budgeting tool that was based off of a CIS or support intensive scale assessment, then they would -- support intensive scale assessment, at a time would run people different through matrix and assign people to budget areas, they sent a bunch of notices you didn't comply, and didn't have appeal rights. The purpose of bringing this up, the settlement to this case led to some changes in how North Carolina operated the person-centered planning process to provide greater protection for person centered process rights. New notices were issued, various stages were made. But one important piece was this communication bulletin to managed care plans and to providers, not the providers, to care coordinators or case managers. So next slide. As I said, based on the new use of the support intensity scale, and one of the biggest issues was that, one of the biggest things that was involved is that it must be clear to families that they can request the services they need not have to stay strictly within assigned budgets. And that no discouragement of asking for service was allowed. We provided part of the settlement with this bulletin that provided sample language which I'll go over some examples next. Which I think will clarify things on the next slide. Part of this multi-page bulletin was a denial or partial denial could not be based on rationales such as the assigned budget would typically meet the needs of someone with similar support needs or that it was determined that the person's name is not an outlier to his assigned category, or that documentation shows needs consistent with the assigned budget category. This type of language was considered not specific enough in discouraging to requesting services. Compare it to the next slide where, the denial or partial denial could be based on more specific language about information and assessments provided to not justify increase in the service hours, or the information provided does not indicate that the individual would benefit from the combination of service hours requested. I know that these are, they don't seem like significant changes, or differences, but they really did make the difference in how people were able to feel like they could ask for services and how care managers or care coordinators were sort of not holding people explicitly to the budgets. And this is sort of this difference between straight out denials of services versus, language that discourages people from asking for services, and for advocates, it can be helpful to be clear that all of -- anything that's discouraging to people requesting services may rise to the level of due process right that should trigger the right to a fair hearing as opposed to a right to -- as opposed to sending the person to the dispute resolution process or a grievance. So for example, if a person's being told stay within this budget, you can't ask for more services, that should likely be treated as a right to a fair hearing as opposed to if you want to complain about that, somebody is like oh, no, that's just a grievance about how your care manager treats you. That shouldn't be happening. And, that's something that you could try to make it clear in Appendix F 1 versus Appendix F2 and 3, and a waiver, right. So what is going to trigger grievances and complaints about how you're being treated versus the services that you're either being provided or you're not being allowed to ask for in terms of denial. Similarly, if a person during the person-centered planning process is not really being given the full array of options about how they could, what services they could request under the waiver, that might also trigger the fair hearing rights as opposed to grievances

or dispute resolution, because that's something they should have access to and request even if they may be denied if it's determined they're not eligible for it based on service definitions. Hopefully that helps explain a little bit the difference between fair hearing and rights to services and you may be -- discouragement of a service or somebody telling you you shouldn't ask for something should rise to the level of fair hearing versus you were complaining at how you are being treated in the person-centered planning process or treated in the service more than that might be more of a dispute resolution or a grievance. I think that is confusing still. But hopefully it gives an example of a sort of real-world solution to sort of setting forth what is the differences between the different things. And I would flag on the next slide that in the North Carolina innovations waiver, which is the waiver this settlement originally applied to, it does not explain all of this. But I think the advocacy point here is that it could. Right. It could describe how the state promises not to discourage people in the waiver from requesting services. And what rises to the level of fair hearing rights versus what rises to the -- what is just going to be treated as a grievance through the managed care plan. So, in F 3 in North Carolina, they really talk more about grievances being more about abuse, neglect and exploitation and access to services, and administrative issues, and quality of care type of issues versus what they have under fair hearing which is much more clear about service denials and term terminations. But for our purposes and the webinar in terms of how can we advocate for waiver documents themselves to really reflect the protections a person should have, I think it could be in F 1, they could be much more clear about when a person has a right to hearing and what is does discouragement look like as opposed to it being a F 2 and F 3 about what the does the grievance system look like in terms of complain about services. So I think I'll pass it back over to Nancy now. We can take questions at the end. I see there's a bunch of questions.

>> Nancy Thaler: Yes. Thank you to both of us. And one, I think this might be our highest number of participants in a webinar and without a doubt, the highest number of questions. Clearly, this webinar hits a nerve. Elizabeth and Elizabeth, can you both see the questions that have come up? And are there any -- some of them are not specific to federal policy that may fall in the advocacy realm. So are there any that you'd like to speak to? As you're looking at them, I want to say that who can you get to help you? There is in every state an Ombudsman's Office, a long-term care ombudsman that can help particularly with people using any waivers that are -- that involve assisted living and home and community-based services. As Elizabeth Prialux explained, the PNAs, there is a PNA that our agency administration of community living funds in every state that's available for consultation and support. And then you know, we hope that when people are enrolled in the Medicaid waiver and have a case manager that their case manager can either assist or help track them to someone who can give good advice and sort through these issues. So Elizabeth, Elizabeth, are there any of these questions? And I believe there are a number of ACL staff on the call so we can try to respond to as many of these as possible. So Elizabeth, Elizabeth, anyone you want to take?

>> I see one about when an appeal or fair hearing is won by families or a person they are voided by the commissioner of DHS. So the family is sort of back at square one and what is their remedy there? This has been addressed by advocates in at least two states by the state actually making the Office of Fair hearings the one who makes the final agency decisions. So

often in states, the Office of Fair hearings is just making a recommended decision in and the state does the final agency decision. So at least in two states that I know of, it might be more now, the state has delegated final agency decision to the Office of Fair hearing, whoever the office is that does the fair hearing decision. The other potential decision, it's very different from other states so we can't provide specific legal advice here, usually there's a mechanism to appeal a final agency decision that goes so far against what the recommended decision was and the standards for that differ wildly by states. But often time -- wildly by state, but oftentimes there should be an appeal mechanism that can sometimes help the advocacy community make sure the state is more closely adhering to when it can and cannot veer greatly away from recommended decisions. Like I said, that varies by state. So it really depends. But I would say that one option is to try to push for the state to delegate the fair hearing decision, the final agency decision.

>> There was a yes about the right to fair hearing and whether or not there's a requirement to have an intermediary activity. And, you addressed this, but, to address this question, managed care is different. You want to talk about what managed care -- why managed care is different and what is allowed.

>> Yes, so managed care just operates under a different set of regulations. They do generally have to follow other ones as well. But they especially for fair hearings and grievances and appeals, they have a different set of regulations under 42 C.F.R. 438.400 that it describes a action differently, it also describes a person that has to first go through the informal appeal hearing with the managed care team before they have access to the State Fair hearing. It's just a rule. I cannot tell you why. It just is something that is required. It's a more recent change in the last couple of years that it is required to go through that info process, it's under managed care that you would have to go through that. If you don't have managed care, there shouldn't be things in the way of access to fair hearing. Some states might have like optional mediation or something like that. But it should still be optional in that instance until we're talking about managed care.

>> Several of you have asked, will the slides be available? Yes, they will be. Erin who hosted us here will have them posted to our website. And possibly be able to insert the link in the chat. There's a question here, which I think was addressed but I want to make sure, if services are reduced, can they be frozen during the appeal or fair hearing process so that people can keep the current level of services pending outcome? And so, I'm going to ask Elizabeth or Elizabeth, Elizabeth Edwards what has -- I think I know the answer to this, but you have the experience across a number of states about what's really going on. So why don't you take that one?

>> I'll pass it to Elizabeth Priaulx because she covered it in her section if that's okay.

>> Elizabeth Priaulx: Yeah, I tried to have a full answer to that -- I typed in a full answer to that and pressed send, I don't know where the response went. I responded to three questions here. I don't see my response which is ignoring. Basically you have the right to, while the appeal is going on, and before the decision, you have a right to request continued benefits. The catch is

that you don't have very long to do so. I think I mentioned that you have the provider has to give you notice ten days prior to reducing or otherwise changing your services. And in those ten days, you are allowed to request for continued benefits. You're also allowed to request a hearing if you believe that the hearing is set for three months away, and this could harm your life, your health, or your functioning. So those are two things that you can get while you're providing. But it's important to note that you may have to reimburse the state for some of the services you received during the pend -- pending the appeal if you lose. So, oftentimes states will make a big deal about this. And it's part of the discouragement that Elizabeth Edwards just was mentioning. Nancy Thaler: Right. There have been a number of questions about managed care. All along the same lines about the requirement to file a grievance. And, what I would say to that, and to the purpose of all of our webinars is that, state waiver programs are optional, and the states have incredible latitude to design how they operate them. And CMS has no stands to require -- there are many, many things CMS has stages to require. Like it cannot require the state to pay family members of family caregivers for instance which has been a question on here a number of times. So advocacy at the state level is enormously important because, states as I said have the discretion to design them the way they want, within the rules. And remember states are paying for anywhere from 25 to 250% of this, so that's what make -- 25 to 50% of this, that's what makes it a state program. As these Medicaid waivers are being developed and we knew every five years, including the 1115, this is the opportunity for advocates to speak with one and strong voice to influence how it's designed and what the requirements are. Strong voice in how it's designed and the requirements are. The states that the latitude to require a grievance process to the MCO, how that's conducted, how that's designed or whether it's even required, very much depends on what goes on between the advocacy community and the state. Because as I said, the state does have the latitude to require that. A number of you can asked about family caregiver, there are a couple of questions about that. But states are not required to pay family caregivers. States may pay family caregivers. The state defines what a family caregiver is, and in many states, there is a reluctance to pay family caregivers. The practice originated with families of medically -- children who have medical complex needs. And for many years that remained the only place. But it has expanded. It expanded significantly through the epidemic. Through the PHE. Now that the provisions, in appendix are being retired, probably by November, six months after the emergency was ended, many states, if states want to continue that practice, I've got to amend their Medicaid waiver to allow that. Not all states are choosing to. Some states may be amending how they do it, but again, it's completely up to the state on whether to do it and how to do it, and even what limits to include. But once the state writes it's rule, once it determines how it's going to do that, I believe the failure adhere to it own rules becomes something that you can either appeal or aggrieve.

>> Nancy, I wanted to address something. One of the questions that is so topical for right now, I answered it and then as soon as I answered it the question went ahead. So I'm not going to be able to say it specifically, exactly, but somebody asked, can you request a fair hearing if your service is denied as a result of lack of providers? And this is happening all over the place. And, well, the state, when it signs its agreement, and when it signs its waiver says that it will have, what's called network advocacy. And it will have a network available to provide the services

requested. So in general, you think of that, like if you had a traumatic brain injury for example, and you require specialized service, and all that was offered was a service for somebody with an intellectual disability, but they didn't have you know, specialized brain injury provider, then you could say that that network was not adequate. Regarding the providers, there have been large class actions for example where the challenge has been, okay, state, you said you would have an adequate network of providers. What have you done to ensure this? And I was thinking about it when you said the state could choose in a waiver to allow family caregivers. That could potentially be an option, if the state hasn't tried that and they're denying services for lack of providers, you know, maybe they should take that step, or have they tried to incentivize people to go into provider rights. I think Elizabeth has been involved with some of these cases. But I think you do have some recourse, the state just can't say sorry we can't provide the providers for the level of services we promised you.

>> There's a question that relates specifically to your information Elizabeth Priaulx. And the question is, if an individual is notified by mail, or there are a couple of these. Are there requirements for how the participant is notified? And is it email is it in writing? How is it done? And the second question is, how the days are tracked. How -- is it -- ten days from when the notice is dated? Can you speak to those two?

>> Awe I can speak to the fact that the notice has to be in writing. That means generally by mail. It also has to be written in a manner that's accessible for individuals. So that's why you get into you know, language proficiency, and things like that. I also know that a state could choose to also provide it via the email. I think that's just a state's choice. Do you have thoughts on that Elizabeth?

>> Typically it is ten days from the date of the notice. It usually states tried to send the notice three days before the actual ten days starts to run But it also -- some states have different requirements or variances on when the ten days to request continuing benefits starts to run or not. So it's somewhat state specific. But the minimum is ten days from the date of the notice.

>> But what --

>> Also -- go ahead.

>> If you have something else to say go ahead.

>> Nancy Thaler: Because we're trying to highlight areas for advocacy around renewing a waiver. One of the ways you can get around the ten-day requirement is if you -- ten day requirement is if you show the notice did not meet the requirements. For example, if it didn't specifically tell you why the service was denied for example. Just cited the statutory citation. So the reason it's a good point for advocacy is that you might want to have them create a sample notice letter or some sort of way to try to prevent these notice issues which could then, you know, affect the time frame.

>> Going back to the point about advocacy, when the state is developing that waiver application, they've got to describe how it is they are going to conduct grievances, they have it dispute resolution if they have it, and how they conduct federal hearings and appeals including I think how they give notice. So again, to get the rules right in your state, the waiver application, when it's under development under renewal, are the best opportunities to affect that.

>> Can I ask it there's a question that's for you, I wanted to clarify something that somebody made a point about. The support against scale I wanted to flag for people. It is true the support intensity scale that says, the website, the CIS is used pretty frequently in I/DD programs. Be you the actual creators of the CIS on the website are pretty clear that it's supposed to be a -- CIS it's supposed to be a guide not a binding decision. Even at times that use it for resource allocation, it shouldn't be a binding decision, there should always be exception processes in that budgets process, that's true of any assessment process and resource allocation. So I did want to flag that. But Nancy, I think there's a question here for you about, you know, when states have notices for public comment, opportunity, and a bunch of comments get submitted then it looks like the state doesn't change anything. What should advocates be doing there? What can they be doing when it looks like the waiver doesn't change a response?

>> Nancy Thaler: Our very first webinar was about how to engage. How stakeholders should engage. And, unlike the federal government, which kind of only does written comments, states did a lot of different ways, and did it a lot of different ways. So the presenters in that very first webinar gave a whole slew of things that they do, including convene meetings, have individual meetings with the state agency personnel, possibly meet with legislators and so, again, the state has a lot of latitude. And while one would hope that what you contribute in comments is going to get factored in, it may not. You may be the only commentator that said that, and there aren't a lot of other people who said it. And that maybe one strategy is for the things that matter the most: stakeholder coalitions get together, and advocate for the most important things that they have. So, all comments, generally I think we can say all comments are looked at and considered whether it's Federal or State government, not all comments get turned into policy, oftentimes the comments conflict with each other, everybody's not on the same page. So, I would say that if you want your point of view known, developing relationships, direct communication, having meetings, working with a coalition, all of those things are important to impress on the state that lots of people think this. The majority of people think this. And Jill you look like you're dying to jump in. Unmute.

>> Jill Jacobs: Sorry, as always I start talking on mute. I actually was looking at a question, a different question on here that came from Ivy Kennedy. And it's a question that asks about attendant pay rates, in different kinds of settings. I'm guessing ivy means consumer directed versus agency directed? And she says that it looks like attendant pay or caregiver pay direct care worker pay is higher in environments that resemble institutions versus a more you know home-based and that may or may not be accurate. I can see why you would come to that conclusion, ivy. And you mentioned ivy that, an announcement from September of 2022, so that ACL was awarded \$3 tenth 25 billion to create a resource center to improve support for people with disabilities so they can live and participate in their community. I think that what you are

talking about is our direct care workforce technical assistance center. And that is getting off the ground. And I see that you see ivy that you've reached oh it to ICL multiple times and haven't -- ACL multiple will times and haven't heard from us. We are happy to talk with you ivy, it's my understanding that you have been in touch with my adviser, Lauren Porino, we look forward to working with you on your concerns.

>> Nancy Thaler: There's a comment about this ten-day requirement, not appreciating that the Postal Service isn't what it used to be. It might be delayed. So I'm sure that creates some complications.

>> You want to clarify something, Nancy. The ten-day requirement is only to request continued benefits. The general notice to request a hearing, the requirement is that an individual must be given a reasonable period to request a hearing. So, that would be able to take into account one would hope the problems with the postal system.

>> Good clarification, thank you.

>> I see some comments about frustration with states saying that they can't do certain things in response to the comments, or, to sort of not responding and I think Nancy covered the not responding thing. But I do think it's fairly common to hear a state say oh, we can't do that, then you can go look and look at the 1915 technical guide which is what sort of these presentations are based off of the waiver and the technical guide that goes with it. See like oh the state actually can do things. It's just choosing not to. So I think although the technical guide is a very long document, it is very helpful to understand like what a state could do, what sort of the big picture limitations of what a state can and cannot do. Then also, they are making certain choices, right. So if you're really trying to dig in on advocacy, I think the technical guide is super helpful. I admit it's long, but you can go through Appendix by Appendix and figure out what -- sort of as these presentations are going, sort of follow along with your waiver, the document itself, figure out okay, what is this thing doing here? What is the state doing here? What could they do? It can be helpful to advocate so I inform your own advocacy about okay, the state is actually able to do these things. This is how they could design the waiver versus what the limitations they actually are functioning under.

>> Nancy Thaler: I agree with Elizabeth. It's important when talking to the states to get to those second and third-level questions. Right. So you know, the state may say, oh, we can't do this. And that reason they can't do it may be because they didn't include it off the ala carte menu of things we could choose. If I didn't choose fries I can't eat fries. The state didn't include some states that are on the Ala Carte menu, that but that's the time to have the secondary conversation and get to though what they could have chosen so you can start to advocate for those things that you think they could have and should have chosen so when that time comes up, you have been very vocal about that and gathered advocates to be vocal apt that in the meantime, you can -- vocal about and and in the mean tile advocate that.

>> There's an interesting question about denial. And, I think it's more than one. But what if -- so the question is, the realm is, what if it's just not included in your plan? What if you ask for a service and the coordinator or the utilization review person says, I don't think you need it. But there's no paper with a notice.

>> I think that's an area in which it's particularly difficult to -- when there's just a verbal denial, this is sort of what we ran into in the Ellis versus Walsh case, because there was both the paper denial about the budget, then there were verbal denials at not being able to access what was called the exceptions process, trying to get an exception to the budget. And what matters there sometimes is really contemporaneous reporting about what you were told. And trying to go to potentially fair hearing based on this sort of verbal denial, that I was denied this on this day by this person, and these circumstances. I have been denied the ability to ask for it. That's a denial. So, you know, this is something that I would really encourage people to seek legal counsel from their own state about exactly how that works. But, there is supposed to be as Elizabeth Priaulx discussed earlier, notice is supposed to be written. And they shouldn't be using person-centered planning procedures to get around notice requirements. So that's sort of why I tried to talk about that North Carolina example where there's that delicate balance between discouragement and helping a person plan their services. Right, a person should be able to sort of ask for what they need, talk about what fits within the service plan and what fits into what the state has designed its own waiver, the person shouldn't be discouraged from ask for what they need, and they shouldn't be told you're not going to get that, so we're not going to ask for it. That could be a potentially a due process violation, and you can still have the right to a fair hearing based on the notice, the failure to provide notice, or -- the failure to provide notice or other concerns around that. I encourage --

>> We should say that the waiver services are linked very much to need, demonstrated need. It's not a service I want or, it's do I need the service? So you're always going back to do I need the service? There could be a dialogue about what you need and another way to get to what you need. So, it's the need that must be met with a service or with -- in the Medicaid waiver there's an expectation that individual service plan will include anything, not the just waiver funded services, but, you know, other services in the community. For instance, Voc Rehab instead of supported employment. Or, there may be an employer who is eager to hire someone and support them so as not to need supported employment services. But is the knead being met? Is linking there you what you're asking for requesting or what you're being denied to the fact that you need it is important.

>> I've seen some questions, I can pull up questions about good grievance systems. I think we get that question all the time. What doesn't bill, I'm not sure of a state that does a grievance system particularly well, I would flag a few things about a grievance system that I think are important. So in a grievance system what you don't want is it treated like customer service. There was a question earlier about data as well. That like what's the data on grievances and appeals? There are supposed to be data reported for managed care about grievances and appeals. But, we've seen a lot of managed care entities treat grievances like customer service. They try to actually talk people out of them and try to sort of say like well, let's try to resolve this

here. But, you really want to make sure that there is still a record of some -- even if they try to resolve it, there's a record of a person complaining about what's happening. That's one thing that I think is pretty critical when you're designing a grievance process. I think that's true in fee-for-service, it's just not until the new rules that have been proposed for under the access rules about a complaint system for fee-for-service, go into effect, I think -- that's just one thing I wanted to flag. That there's this delicate balance there about customer service versus tracking complaints.

>> Nancy Thaler: I can't help but call attention to, I'm going to try to put it in the Q&A session here. CMS has released a new proposed rule one of the major features in it is requiring states to have a grievance procedure, they're asking for comments about what CMS should require states to do. I'm sure Elizabeth, both Elizabeths have lots of ideas about that. I would strongly encourage people to work with coalitions, CMS doesn't need a hundred million comments. They need comments from people, with letterheads, and experience, and valid background that can say, this is what we think should be in there. There are a number of other things in the access rule including requiring states to have an electronic incident management system and defining what incidents have to be reported. There's a section about person-centered planning and requirements for that. So, I'm going to try to assert ACL itself published a blog that explains all of these changes. Erin, if you have it handy before I do, the link for the blog that includes the description of all of those, I have the email with it, not the link to our website so that you can see what those six or seven major sections are. And how it is you submit comments and the comments are all due to CMS by July 3rd. So we have a couple of months.

>> There's also a piece in there about, I noticed a couple of people that asked about how much money actually goes to a provider, to the actual care, like the direct care worker. And the access rule has an element about that in there. So for example, if I have a home health agency, the suggestion and the access rule, what is stated the access rule is that 80% has to go to the actual direct care worker, 20% can be used for that home health agency for overhead or other sorts of expenses. Is that an important piece.

>> I just wanted to add to what Nancy said about grievances. Regardless of the new rule which is amazing, even right now, a grievance policy has to make clear that it tells people that a grievance is not a substitute for a fair hearing. And, then in fee-for-service, again they don't even have to have a grievance procedure, so that might be something that you want to push for.

>> I think that I'm seeing several comments or questions about people being sort of pushed towards the dispute resolution rather than a fair hearing. I think it can be common that a state, within a state people are sort of pushed towards complaining about providers or complaining, using the grievance system to complain about lack of services. But as Elizabeth Priaulx discussed earlier in the presentation about the right to fair hearing, fair hearing is when a service is denied, terminated or reduced or when it's not been made available with reasonable promptness you can file for a fair hearing. So that actually covers a lot of situations. Now whether or not your appeal hearing officer, you know, pays attention to all the things they

should, it's a different question. But if that is the purpose of a fair hearing versus grievances, and dispute resolution, typically even under managed care grievances and dispute resolution should be more about sort of dissatisfaction for treatment versus lack of access to services. There is an area where if you're having trouble finding the type of provider you want that could be a grievance. But if you really can't get services that can often go more through fair hearing.

>> I will admit I think there's been a lot of questions or comments in the chat about sort of lack of access to help. And I think, Elizabeth Prialx from her perspective would probably agree, and correct me 23 I'm wrong, we push the PNAs were much bigger than they are. But they have limited federal funding to do work and similar with legal services there, there is a lot more work that could be done than capacity. Nancy Thaler: We fund the PNAs and the ombudsman offices as well. Don't forget them as well. A you awe I think we put the ombudsman link in either the Q&A section or the chat. People can look at. So we are coming to the end of our time here. We've got 2 minutes left. So we appreciate everyone participating. So, so pleased that there's so much engagement, that there are so many people here, I think we had 395 people, or 402 at the height. So I think we're really really pleased to hear that so many people participate. We ask you to continue to participate in these webinars. We need to hear from you. We enjoy the interaction and the conversation, we do consider it a conversation. Thrilled to see we had so many questions. I know we didn't get to all of them. I think we got to about 60 or 70%. So we're going to leave a minute to fill out the webinar, fill out the webinar satisfaction, if you can do that it really helps us for next time. A

>> I want to say Erin has posted the new ACL which explains the new proposed rule and the grievance procedures for you all to read and digest. As are filling out, I really want to thank Elizabeth and Elizabeth from DRN your presentations are really great. Your vast experience as advocates I think really provided a rich context for these questions. Thank you.

>> I don't see you fill that out, I would like to thank Erin Shay who coordinates all of these things, and making sure that we are all on top of what needs to be ready for our webinars. And Marcia Gordon who faithfully always gets us through, making sure the links are working and gets the speakers and panelists ready for the webinars in the moments before you all arrive. We'll keep this open for about another minute. So people can finish answering their questionnaire. And we hope we see you at the next one.