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**SPEAKERS**

Susan Koller, Kate Brady, Elizabeth Edwards, Jennifer Kucera, Laura Bernas

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K **Kate Brady** 00:00

Welcome, folks, to the Grassroots Project webinar. This is a project administered by the Human Services Research Institute with funding from the Administration for Community Living (ACL). My name is Kate Brady, I co-direct this project and work at the Human Services Research Institute. For a brief visual description, I am a middle-aged woman using a wheelchair with short brown hair, glasses, and a kind of multicolored dark blue shirt, and there's art on the wall behind me. We are very pleased to have you with us. This webinar today will be entitled "Tools and Tips for Commenting on 1915(c) Waivers." Before we dive into that, we'd like to share some logistics with you. We'll have some great presentations from panelists, including Jennifer Kucera from the Ohio Olmstead Task Force; Susan Koller, a self-advocate; and Elizabeth Edwards from the National Health Law Program (NHeLP); then, we'll have a facilitated discussion. Here on the screen are the Grassroots Project team members, though we have expanded a bit. So you'll see here our Co-Director, Alixe Bonardi, who is also the Vice President at HSRI, myself, and then our wonderful Project Manager, Laura Bernas, who is with us today. We also have an excellent project evaluation partner, Amie Lulinski, and Loralei HoJay, our Advocacy Fellow. And there are phenomenal other contributors to this project, which is in its first year, and supported by a great many national, state, and local advocacy coalitions. So some opportunities for feedback—we would welcome your follow-up questions and feedback about the webinar. You can send that to us at grassroots@hsri.org. Our webinars are not officially approved for Continuing Education Units (CEUs), so you won't be able to get CEUs from viewing this webinar. Our materials today—the PowerPoint and anything else that's shared, including a plain language summary and transcript—will be made available and archived on our project website, which you can find on the HSRI website. So, a little bit about the Grassroots Project itself. We were launched in 2023—although this is our first full year at this scale—and our aim is to support national, state, and local disability coalitions and advocates in building networks that allow them to stay informed about policies that affect people with disabilities. We also support grassroots disability advocates to work together to ensure that their perspectives, priorities, and preferences are reflected in disability policies, as well as service systems. On the right of this slide, you'll see an image with circular shapes nested inside of each other. This is meant to share a bit with you about the structure of the project. We work directly with people with disabilities, as well as Local and State Advocacy and

Action Coalitions, and National Advocacy and Action Coalition members who are representative of the Developmental Disabilities network and the Independent Living network, as well as behavioral health advocacy, chronic illness advocacy, autism advocacy, and paralysis advocacy, as well as self-advocates becoming empowered. We're really thrilled to have a broad network of national partners that comprise our National Advocacy and Action Coalition (NAAC). We're also pleased to have a State Agency Partnership Group (SAPG). This group is an advisory body, and allows us to be in communication with the national organizations whose members are state agency leadership. This is phenomenally important because in the Grassroots Project, we believe that change is made through bi-directional efforts. So that is, it is important to be speaking with people who experience the service systems that we're concerned with, and it's important to be speaking with people who run those service systems, so that people with disabilities can have a more meaningful part in system design. And then we've already mentioned that we are currently partnering with a cohort of 11 State and Local Advocacy and Action Coalitions around the country. Our approaches to doing this work include the aim of developing structures, processes and relationships that allow us to build and support a cross-disability, cross-generational, and culturally-diverse advocacy movement, and we are hoping to connect, grow, and strengthen networks of grassroots coalitions such that they can be supportive of one another in growing skills and knowledge to advocate for quality community living. Because we are federally funded, it is important to note that when we say "advocacy," we mean the "little blue" advocacy on the right [of the slide]. So those are activities like education, information dissemination, preparation, and organizing. We are not—in the context of this project—doing direct action or lobbying. So, on to the webinar today. This is the fourth webinar hosted by the Grassroots Project. It brings together the National Health Law Program (NHeLP) experts with individual advocates from the state of Ohio, and we will be exploring the experience of commenting on the 1915(c) waiver. The webinar will touch on technical skills that have been expanded upon in NHeLP's "Commenting on Section 1915(c) HCBS Waiver Guide," which was a product produced in the context of the Grassroots Project last year, and we anticipate will be very valuable to the community. So we'll hope to reflect on that today, and we want to hear about the experience of people using that tool, and those who commented on the waiver independent of that tool. So that's what we're up to in the webinar. It is my pleasure now, to turn it over to Jennifer Kucera from the Ohio Olmstead Task Force.

J **Jennifer Kucera** 09:04

Hello, everybody. My name is Jennifer Kucera. I live in the Cleveland, Ohio area. I am a white woman in my mid-50s. I have my hair pulled up in a ponytail, a blue colored shirt on, I was born with a disability, and in my background, you'll see my wall with some frames on them, and right behind me is a gray large pillow. I'm glad to be here with you today. I also use the pronouns she/her. We're here to talk about a group that I currently chair, which is called the Ohio Olmstead Task Force. We were actually started in 2002, when advocates started meeting in Ohio to get their Medicaid agency to take them seriously. This was right after the Olmstead decision was passed, which was in 1999, and Ohio wasn't doing anything to help people to move out of facilities. Those that were out of facilities were really trying to help their friends, to also move into the community of their choice. So they work together to form together, and group together, and add the help of the National ADAPT organization. They actually waged a sit-in in one of the federal buildings that we have in Ohio, until the Medicaid Director would finally sit down and listen to them, and take the Olmstead decision seriously. We have continued to grow since that time, and we have advocates from all across our state that participate in our meetings. Besides people with disabilities and their family members, we also have different organizations that participate right alongside with us in our committees and in our monthly meetings—Area Agency on Aging folks, people from Managed Care Organizations (MCOs), and people from a lot of different organizations and agencies that work with people from with disabilities across our state. So we have a lot of buy-in, and again, you'll see some of the other organizations listed on the slide. Centers for Independent Living are directly involved with us, the P&A System in Ohio, and a lot of others. And we do a lot of advocacy work, again, with the lower case "a," because we are a 501(c)(3) stand-alone organization. Because of the Olmstead decision, it was mandated that every state has an Olmstead Task Force, but we are a stand-alone one. We are not connected with any agency or government or cabinet agency in the state, so we are able to have a little bit more freedom to do what we want to do. Our mission statement is to advocate, educate, and support change for all people with disabilities, ensuring their right to participate in a thriving community life. So anything that has to do with community living, Olmstead is on it, and we do statewide advocacy work, for the most part. We do a little bit of national stuff now, but mostly it is statewide work. And our vision statement is similar, saying Ohioans with disabilities shall have access to inclusive, integrated, and person-centered services and support tailored to their individual needs to live independently in the community. So we are very much living out the social model of disability, and the independent living model of disability. So in Ohio, we have a very complex system. As far as our waivers go, we have three cabinet agencies—so those are the ones that are within our government, that are responsible for Ohio's waivers. We have the Ohio Department of Medicaid, the Ohio Department of Aging, and also the Ohio Department of Developmental Disabilities. I have a breakdown here on this slide of each of the departments, and the waivers that they're responsible for. So the Ohio Department of Medicaid has the Ohio Home Care waiver—this is really our fee for service model. And then we also have a Managed Care waiver called MyCare Ohio waiver. The MyCare Ohio waiver is the one that I actually utilize. So those are the ones that are governed by the large Managed Care companies. Then over on the Aging side, we have what we call the PASSPORT waiver. And then in the Department of Developmental Disabilities, we have what we call the DD waivers, and they're all basically still a nursing home level of care waiver. But there's a little bit of nuances between, and obviously different services that all these waivers offer, so there's a lot of differences. But within the Ohio Department of Developmental Disabilities, there are three waivers. One is called the Individual Options waiver, or the IO waiver. There also is the Level One waiver, and then the Self waiver, which is the Self-Empowered Life Funding waiver. The IO waiver is the most—besides the other waivers with Medicaid and Aging—the IO waiver is the most populated out of any of the waivers in the Department of Developmental Disabilities. The Self waiver, the last one on that list, is more of our self-direction waiver. So those folks don't need a lot of services, but they do have self-directed caregivers. So hopefully that makes a little bit of sense. But we do have a lot of waivers in Ohio, and a lot of folks don't even know which waiver they are on, which could be a problem. I know the Ohio Olmstead Task Force is really trying to encourage people and teach people how to comment on their waivers. And if you've ever looked at a waiver, you know that it is a huge task to undertake, to even read through the waiver, and then make comments on it. Some of the difficulties that we see in Ohio, that I have personally seen, are really understanding the waiver system, because all the different waivers and all the different ways that they're funded—predominantly through the Department of Medicaid—all the different services they offer, it's really hard to keep it all straight. Just that, alone, is very, very difficult. And then when they do the open comment period, if you are not a member of the agency's newsletters or their emaill listservs, you have no idea when the commenting periods are happening. And the letters are very formal, they are not written in plain language, so they're very difficult to understand and to even know where to find the information. They do have, on their individual websites, [published notices of] when the comment period is open, but unless you're in the know, it's hard to know. So one thing that we try to do at Olmstead is to get the information out there to people in a usable format, usually in plain language, to just explain what the open commenting period is, and how to find everything. And then there's also the general difficulties with the waiver document itself. I, for the first time, numerous months ago—I think it was towards the middle of the end of last year—I had the opportunity to read the waiver document. I had never really ventured into it. I had no reason to. But then some of the commenting periods opened up, and there were three different waivers that we, as Ohio Olmsteaders, wanted to comment on. And that waiver document is over 100-some pages long, and it is not easy to read. It's what I call that "legalese." So I had to read several parts of it over and over and over again, to even make sense of any of it. So these are some of the techniques that we used in Ohio. I definitely could not read three waivers all on my own and make public comments. So several of the advocates, we all got together, we had numerous meetings about our plan of attack, and we decided to divide and conquer. Each one of us took a different waiver, and we used Adobe Acrobat to open the document in, because you can do searches on there, you could highlight information, you can copy-and-paste text—so whatever reader you use, hopefully you have those features available to you, because they were very helpful to us. So then we just started taking key pieces of information, and even questions that we had because we didn't understand everything, and we just kept meeting with each other and talking through our different waivers, and we finally came up with documents for each waiver, with comments that we were able to submit for public comment. They were long, we tried to cut them down as far as we could. There were also sections of the waiver that we did not even comment on, because we felt like we didn't have enough understanding to even comment. So that's okay, you don't have to comment on every single part of the waiver. Could just be one thing that you don't like about your services that you receive. So, we tried to talk amongst ourselves numerous times before we submitted. Then we started reaching out to other people, as well. So we were collaborating with other organizations on the different parts that we did not understand. We reached out to some of the Managed Care companies to ask them different questions, especially about how the payment structures work, and various other organizations across our state to just learn more about the waiver document itself and the different components in it. So those are the techniques that we used in Ohio.

K **Kate Brady** 20:42

Thank you, Jennifer, it's so interesting and helpful for us to hear your efforts in the Ohio Olmstead Task Force. We are now going to get to hear from another Ohio waiver commenter. Susan Kohler, I'd like to invite you to the screen so that we can have a little discussion. And before we do that, why don't I let you introduce yourself and give a little visual description.

S **Susan Koller** 21:17

Okay, sorry about that. Hi, I'm Susan Koller. I'm a white woman in my early 40s. I am in an electric wheelchair because I do have cerebral palsy, and I have glasses, I have short brown, almost shoulder-length hair, a bright blue shirt I'm wearing, and behind me you can see some of my bedroom, mostly my closet door and my touch doors, and if you look very closely, a picture of a dog. And before we get into our questions, Kate, if you don't mind, I wanted to take a minute to let the audience know about certain things. As you guys can probably see now, my eyes are closed and my head might be going all over the place. That is not disinterest in what I'm talking about. It's more that my CP makes it hard for me to do two things at once, which is like, looking people in the eye [for] long, concentrating, and giving answers. So I apologize for that to the watchers of the video, and I do know I have a speech impediment. So Kate, if you or any of the other panelists cannot understand me at any time, please just feel free to ask me to repeat myself. You won't be the first person and you won't be the last, but I did want to make why you see certain motions in my body clear, before we started our Q&A.

K **Kate Brady** 23:02

Thank you. I think that's really helpful context. As I told you before we started, it's never occurred to me to do that about my own communication, but I'm definitely gonna give that some thought. But now, Susan, we'd really love to hear from you about your experiences, and I thought we might start just by understanding what led you to becoming a self-advocate and submitting waiver comments in the first place. Sort of a bit about your journey.

S **Susan Koller** 23:37

Sure, and this is kind of a long answer, and so I will condense it as much as I can. To be perfectly honest, for the longest time, I wanted nothing to do with disability advocacy. I figured my disability took over enough of my life. I was happy just doing PR work. I was living with my mom at the time. I did have the Ohio Home Care waiver, I got it when I was in grad school, when I needed home health care aides to come into my dorms to help get me up. And I remember that first meeting, but to be honest, at the first meeting, or whenever you talk about a waiver with any case manager, regardless of the system, you know, you get so overwhelmed that you don't really know what—they give you so much information, and you don't really have time to go into it, so you know, you're just living your life. And that worked well for a long, long time. I probably didn't use all the services that I needed to, because my mom could do a lot of my care. So I would have people come in three times a day for two to four hour periods to help me out, and then my mom would just do the rest of my care. I did at one point, start looking into moving out on my own. But to be honest, I require so much care, everything from helping me get a drink of water to putting me to bed, and you know, in the bathroom, I need help with the toilet. So I wasn't sure, to be honest, if I could move out on my own, with the limited amount of hours under the Ohio Home Care waiver, and my family members were a bit nervous about me staying overnight by myself, because in bed, I can't do anything. Well, everything was going smooth, and then we hit 2018. Like I said, I was living with my mom, and I had started thinking about moving out and stuff like that. But then all of a sudden, we could not get those caregivers that sort of supplemented the care that my mom gave me. And I got kind of scared. I'm like, oh shoot, my mom is my only caregiver. When she gets older, what happens if she falls or if she breaks her leg or anything, what will happen to me? And I had heard horror stories about what could happen to me, so I was kind of worried. So I actually made the very unconventional choice of moving into a long-term care facility. Now, the facility did not use the word "nursing home" in any of the promotional materials, because that would have given me a clue. And it wasn't your typical nursing home. It was just for people with disability, with neurological conditions. They had overhead lists in all the rooms, and I was by far not the youngest person in the nursing home, so I thought I'd give it a shot. And to be honest, the reason I chose the nursing home, was [because] I knew if I moved out on my own, that I would probably need a lot more care. And I'm just not good when I have someone underfoot, I'm very independent. I need a lot of help, but I also like to do my own things. So I naively thought—and this will really show my naivete—you know, I'll go into a nursing home, ring a bell. Someone will come take me to the restroom very quickly, and I can just go on and do my own, you know, work and stuff. Oh boy, that is not what happens in nursing homes. Nursing homes have a lot of a lot of restrictions. But to be honest, they are so busy and they have shortages, so you could be waiting a long time and not even get to go to the bathroom because of the shortage and the intense work. So I'm like, okay, I can't stay quiet anymore. I have to do something to address the shortage, which [was what] first made me sort of move out of my own home, if you will, and then it's also affecting the nursing home. So I linked up with the Association for University Centers on Disabilities (AUCD)—and there are centers in all the states, and we have a center in Cincinnati. So I took a year-long advocacy course as a self advocate. Interestingly enough, because this is a very important part of my story, I didn't know I had what would be considered a developmental disability until I got into my UCEDD course, and learned I did. And that is very important in my story. So then I was like, A) In my mind, I had always wanted to try independent living, and B) I'm like, well, if I'm going to be waiting long hours for bathroom trips or services that I need, I might as well be waiting at home or waiting in my own spot with a dog. I had a dog when I was at my mom's house, and which is what I sorely missed. So at that point, I was on the board of Disability Rights Ohio, which is Ohio's Protection and Advocacy organization. So I sort of cheated. I took the easy way out, and called them and said, What do I do if I want to move out of the nursing home? And they told me, they let me know that I had two options, basically. One was the Ohio Home Care waiver, which we have referenced before, but again, because I am eligible for DD services, I am also eligible for that IO waiver that Jennifer mentioned. And the IO waiver is basically the creme de la creme of waivers, meaning you can get 24 hour care, basically. And I sort of feel like I cheated the system. People want people in facilities to get out. So there's such a thing as an "exit waiver." There are certain amount of slots for each waiver—and maybe someone else will go into this in further detail in another part of the presentation, so I won't go into detail—but they save a number of those slots just for people getting out of nursing homes, because they want us out of nursing homes because it's more expensive for us to be in nursing homes. So that is truly the only reason, I believe, that I quote unquote "skipped the queue" and got this waiver. I believe, had I been still living at home with my mother, and tried to move out from there—because DD waivers in Ohio are done at the county-level, and I was in the county that doesn't have a lot of funding, they would have said, "Oh, we're sorry, you have your mom to take care of you, this isn't an emergency need." So I'm not sure, even though I was always eligible for the IO waiver, I would have gotten it, had I not been in the nursing home when I was. So after that, I learned how important waivers are in my life. Basically, I can't live without a waiver, to put it bluntly. I need help getting out of bed, even getting a drink of water. So I wanted to get more involved with the process, and I did that through two ways. I am a member of the Olmstead Task Force, which is wonderful because, as Jennifer referenced, they nicely send me notifications of when it is available to comment on a waiver. Because even though I get all the newsletters from the departments, sometimes those little comment periods are like—they're in the newsletter, they're written down, but they're so small that you can miss them, the information that it's time to comment. And then, I also was a part of another AUCD group that just focuses on waivers, and that I believe is involved with the Grassroots Project, and that is how I learned the most about commenting, and truly how I got involved.

Kate Brady 34:33

Wow, Susan. What a journey you've been on from prioritizing your own life outside of disability, as you said, to moving twice and navigating numerous different waivers. I'm so glad that you're situated now, with a waiver that provides supports. I'm wondering if you might reflect on the work you did after your experience with the LEND program around waiver commenting, and what was challenging about that waiver commenting process.

S

**Susan Koller** 35:19

Sure, and I'll be repeating a lot of what Jennifer said—but just the sheer size of the waiver. I believe when I went to read my IO waiver, because I'm like, if I'm going to do this, I'm going to know all about it, as much as I can. I believe it was 583 pages. So I was like, oh, my goodness! I mean, that in itself is intimidating. I felt like I needed a law degree to understand it. Or, if not a law degree, at least a degree in state government, because it's always referencing different state laws and codes and all that good stuff. And then, it is not, as Jennifer said, in plain language. I was sitting—I had my waiver, my comment document, and my Google document open at the same time to Google every time I didn't understand. And trust me, there were a lot of them, like rate methodologies. Even though I read it, and I read the formula on how they on how they figure out what each service costs. Yeah, it still makes no sense to me. The one thing I will say is, I've now commented twice on waivers, and it was a lot easier the second time around. So for all of you who are watching this video, who are totally intimidated, it does get easier, mildly. And I had, I had people like Jennifer, and at AUCD, that I could talk to for feedback, and say "I don't understand that." And in my comments, I literally said, I would make better comments if I understood this document better. So that was my first experience, but like I said, the second time got better.

K

**Kate Brady** 37:46

Well, that's good to hear, that the second time got better. And I'm also hearing a call for plain language waiver documents, which we've heard elsewhere, as well. So, last question for this segment. Susan, I'm curious, other than a plain language version of the waiver, are there other support resources or guidance materials you think you would want?

S

**Susan Koller** 38:19

The two things that I think would be great, is like, a glossary of terms provided with the waiver. And like I said, the original waiver document is 583-some pages. So what I said in my second round of commentary was, it would be wonderful if, when there was a call for comments—now they do have a summary in the very beginning of the waiver section that summarizes all the changes, which is very helpful—but I was always curious if they could just publish the amendments, and everything related to the amendments, instead of going through the whole waiver itself, if we could just have a condensed guide with just the changes and the sections those relate to. If that makes any sense?

K

**Kate Brady** 39:32

It does. Yes, you're saying, for changing or amending the waiver, could we highlight what section has been changed, from what to what? And just provide that.

S

**Susan Koller** 39:45

Yes. And I do know it's highlighted in the first initial pages, but if you could publish the document with highlighting what the changes are, along with what the changes are, just document with highlighting what the changes are, along with what the changes are, just publishing those sections of the waiver that those changes pertain to, so you don't get lost in things that aren't relevant. And then when I comment on waivers, I always add a little thing that I say. I'm like, I know this isn't in this comment period, but by the way, I'd love—and this is the one I always use—I'd love, when you're changing your rate methodologies, which I do not understand, maybe someone could publish something on rate methodologies. Could you please pay more? Could you give the DSPs or direct care workers, a higher rate? I don't care what else you do. So I always include tiny, tiny comments like that. I figured if they keep hearing it, they might do it sometime.

K **Kate Brady** 41:06

Yeah, I like that thought. I like your approach. The burden of sorting the comments is on the recipients. The comment period is open to you, saying and providing any feedback that you want to provide. So thanks for lifting that up, Susan, and thanks for reflecting on this journey you've been on, and your efforts to comment. We'll go now to Elizabeth Edwards from NHeLP. Welcome, thanks for being here.

E **Elizabeth Edwards** 41:44

Hi, everyone. My name is Elizabeth Edwards. I'm a white woman with long, brown curly hair and glasses, and there's a bookcase and some other things on the wall behind me. And I am here today to talk more about how the waiver is structured, and try to address some of the things that Susan and others have said about how complicated these are, and try to demystify it a little bit, because, as they've talked about earlier, it can be complicated. But there are ways to kind of look through the 300 or 500-page documents that may be out for comment, and actually just narrow down and say, this is the thing that matters to me, and this is what I want to comment on, and where you can find it in the waiver. So, one of the things that we've done through this project is, wewrote sort of a toolkit or guideline for how to read the waiver, and where things may be found in that document. And I'm just going to cover some of the basics today during my part of this presentation. So as everybody's already talked about, why even try to comment? The first one, of course, is to change the waiver. As we've talked about already, it can make a difference, because states don't always fully understand how a waiver works on the ground. So for example, they may have a service definition for personal care or something similar, that is provided by the waiver and have limits on it, or may have criteria about how and when it can be provided, and they don't really understand that that doesn't work for how people live in their everyday life, or how it may restrict how people are using the service in a way that wasn't intended. So, of course, one of the things you can do is tell a state, this isn't working for me because of X, Y and Z, and this is what I think should change in the waiver. So sometimes it's a lack of understanding, and sometimes it's just, you know, maybe a bad policy, either reason doesn't really matter. What you're trying to tell the state is, this doesn't work the way it's set up. The other thing about commenting on a waiver, is that it's one of the few structured opportunities for feedback on waiver issues. So, unlike writing the letters to the state, or trying to have a meeting with them, or providing public comment in a broader open meeting—with the waiver comments, the state is expected to respond in the final waiver document they submit to CMS, the Center for Medicare and Medicaid Services. And that information does get funneled into CMS as they approve an amendment or an extension to a waiver. They won't actually see your comment itself, but it will be a summary, and the state is expected to respond to it. So at least, just sort of getting information to an authority above the state about your experience with the waiver. The other reason why you should comment is, it can be the basis of further advocacy to CMS about how the waiver is working in your state. In any state responsiveness issues you have, for example, you may follow-up your comments to the state on the waiver process with a letter to CMS that says, hey, as you're looking to approve or disapprove what the state has submitted, here's some things you should know about how this waiver operates. Now, I will tell you from the get-go, that you're unlikely to actually get a response from CMS, but the point is, they have the additional information. So, as I think Jennifer mentioned, if the waiver is being amended, there is a summary of what's being changed in the first few pages of the waiver. So there is a way to look quickly to see what's happening. So, quick rundown of what is actually involved in 1915(c) comment requirements. So, the state has to allow a comment period of at least 30 days before submitting a proposed change to CMS. As others have said already, it can be a very long document, and it can take a while to try to figure out what you want to comment on, but don't be intimidated by that. You can certainly do this in the time that's allowed. CMS can allow some changes to be retroactive, or, for example, go back in time, but usually not, so everything the state wants to change about a waiver, it has to submit an amendment, and it has to allow for public comment before they actually change anything about your waiver that's within the waiver document. And as I said, the state must then summarize the public input on the waiver. And you can actually look at how they summarize your public comment in that section, 6.I, and they are supposed to explain why any comments were not adopted. They don't have to respond individually to people, but they are supposed to summarize it. And sometimes you can read that summary and feel frustrated, but at the very least the state saw your comment, heard it, and is having to summarize it to CMS. So as we've talked about already, these waivers are very, very long, but I don't want the length of the waiver to be intimidating to you. And it can be very confusing, as others have talked already, as well. One thing to know, is that every single waiver application uses the same, clear structure. They all use the same document that they then fill in. So once you become familiar with how they're structured, you can find stuff in them easier. As Susan just said earlier, once you do it once, it's a little bit easier to do the next time around. And also, there is what they call the Technical Guide. It's a manual for states about how they're supposed to fill out the waiver, and what are the guidelines or review criteria that CMS will use. This is also a very long document, but it is structured just like the waiver application is. So if you have a question of like, what does this mean in my waiver, you can go to the Technical Guide, to that same section, and see how CMS says a state is supposed to fill it out. And so we did create, as I mentioned at the beginning of this section, "Commenting on Section 1915(c) HCBS Waivers," a guide for common issues that I believe is available on the Grassroots Projects website. And it's supposed to help you understand where you can find specific issues—like, if you have problems with your services, you can go to Section C, Appendix C, and look at services. And we have some questions and guidance in this commenting guide to help you figure out, how do you maybe want to talk about, or comment on that issue? So, for example, in the basic structure, if you want to talk about eligibility—and I think somebody said earlier that there's reserve slots for people trying to exit facilities—you would look to Appendix B and say, okay, where are the reserve slots? Who has access to them, and how many are there for people exiting institutional settings, like nursing facilities? Your state might not have any, or your state might not have enough, but you can look at Appendix B and say, this is not what we want, we want something different. So the other big one, of course, is Appendix D, where the person-centered planning and service delivery requirements live. And that can be where you may want to say, this doesn't actually happen like this on the ground, and the state needs to do something different in order to actually meet person-centered planning principles, and not just be a not-very-helpful process like it is in some states. So what are some common issues that you may want to comment on when you're thinking about, what should I comment on [in] waivers? And why should I comment? So, as I mentioned before, you may want to comment on eligibility issues. It may be that the state doesn't allow as many eligibility groups into the waiver, or maybe they don't have the income level high enough so that maybe there's people who are just over the income limits, and if they raised it a little bit more, it would cover more people who need care. You can also talk about services. A lot of issues happen in waivers around services, including who may provide those services, or what kind of limits there are on services, or whether or not you can pay family caregivers to provide those services, and any limits there may be on them. There's a lot of issues that are in services, that comments can really impact how the waiver actually works for people. I also wanted to flag cost limits. Often, there are issues that people experience with budget-setting by states in limiting the amount of services they can get. States can actually make different choices around overall cost limits for somebody in a waiver, and they can also talk about individual budgets. So if any of those things are affecting access to services under a waiver, or maybe the ability to do all the things you might want to do in a waiver, then the cost limits section might be something you want to comment on. I also talked briefly before about person-centered planning processes. This can be, really an area of problems where perhaps a care manager or case manager is saying, don't apply for certain things, or don't ask for certain services, or somebody's wishes are being overrun by others in their person-centered planning process, when that's not supposed to happen. So you may want to make some comments on that section. And then, of course, Susan mentioned rates paying the direct support workers. The rates section is pretty complicated. I think that ultimately, you don't really have to understand all of the rate section to [be able to] say, this is the rate that they're paying people for the service, and it's not enough for X, Y and Z reasons. I wanted to take one particular example to talk about, how do we actually comment on services? So, Appendix C in a waiver is probably the biggest part of a waiver. It's the most number of pages. It's where the state lists out all of the waiver services, who can provide them, what the service is supposed to do, and any limitations on the service. It really is the heart of a waiver. And so, this is one area where you can look and say, okay, the waiver provides home supports, but here are the limits, and here's why the limits don't work, and that's what I want to comment on. And so, like I said before, the common area for disliked limits, are things about how budgets apply to limits on services. States may limit services by level of support. So, how they've assessed a person and said, you don't need X number of services, because we've [determined] that you have this [other] level of need. Also, there may be restrictions in the services section about how services may be combined. Sometimes, what you want to point out in comments is that there's actually limitations that a state applies to services, that are not actually listed in the amendment, and are notappropriate and are restricting your ability to use services like you want to. So, like I said before, one of the biggest things that advocates and people who are more familiar with how waiver services work, is to describe "how does this work on the ground." So one thing to know is, of course, that CMS is working with all of the states, and every single state's waiver programs are different. And as somebody who works with a lot of different states, I can tell you the waiver programs are often very different, including, what does a service mean? So, personal care in one state may look very different from personal assistance in a different state, even though it has a very similar name. So one of the things that's really valuable about commenting is, you can describe how does this actually work on the ground, and what are the problems with it, and how does the waiver not allow people to be in the community as much as they want to be, or not have enough support. So it's a really good way for CMS to understand, how is that waiver actually working? The other really good thing about commenting, is it's a great opportunity for addressing issues with, how do all of the services work together? So, for example, if you can get community supports, but can't get community supports on the same day as another service, that can be a problem with service design. You can also, I think as both Susan and Jennifer said, just ask questions that really ask about, why there are those limits on services, and why they don't work. You can also ask about exceptions processes, for example, saying there's a limit on this service, but I actually need five more hours a week because of X, Y and Z, and there should be a process for me to ask for that and also be able to appeal it. And then there are supposed to be safeguards in the waiver for what happens when a limit says you don't get as much services as you need. You can be commenting about that, as well. So there's a lot you can actually do with waiver commenting. But, one thing I really want—and I think we have all said this during this presentation—you do not have to understand everything about a waiver to write an effective comment. As I said before, all waivers are different, and what you really are trying to do is say, here's how I'd like my waiver to change, or here's what's in the waiver that doesn't work for me. And that's really the most valuable information that anybody has when commenting on a waiver. Why doesn't it work? What don't you like? What would you wish is different? And one thing that is particularly helpful, is to provide examples. So, saying "I don't like how personal care is limited in this way, because I can't do X, Y and Z because of that limitation." So it's really helpful to provide an example of, how does it work in your situation, because as much as state people and people at CMS are very knowledgeable about waiver policy and home and community-based services, they often don't know how waiver services work in real life, and why some things don't work in a functional way. So I think that's one thing to really say, you don't have to know what all the terms in the waiver mean. All you need to really do is say, this waiver is not working for me because of X, Y and Z. And the more you can target that to anything that's been changed in the waiver and is officially up for comment, the more effective you can be. But, I will say, all comments are helpful regardless, and it doesn't really matter if you comment as a group. So for example, if you all get together and create a letter that's a sign-on letter, that's effective. Commenting on your own is also effective. At this point—you used to be able to say, oh, the number of comments really mattered. I don't think that's as true anymore. So just know that any comments are helpful, no matter how you want to do it. It's also helpful. The key is just providing information to the state about how the waiver does and does not work, or how it can be improved, and then following-up to see if that actually made a difference, or how did the state respond to that request. So, inform your advocacy next time around. Or, maybe you're going to advocate with the legislature about something to force the state to make a change, or other ways you're going to use this identification of issues in your waiver, to further advocacy.

K **Kate Brady** 59:18

Thank you very much, Elizabeth. That's so helpful, and we'll make sure that people have access to the very excellent guide that you all produced. And it's really helpful to have an overview. At this time, we are going to move to a discussion with the panelists. So I'd like to invite folks to come on screen, and I'm actually going to take this slide down, and we'll have a little discussion. And to kick us off, I'd like to introduce our Project Manager, Laura Bernas, and let you say hello and give a visual description.

L **Laura Bernas** 1:00:17

Hi, everyone. My name is Laura Bernas, I am the Project Manager for the Grassroots Project at HSRI. I use she/her pronouns. I'm a white woman in my early 30s. I have long, brown hair that's half-up in a ponytail. I'm wearing turquoise glasses, and a navy blue dress with blue and white flowers on it, and I'm sitting against a purple chair, and in the background is a cabinet, and then some art and costume pieces. So yeah, so, really excited to be with everyone today, and thank you all for the presentations you've given so far, and everything that you've shared. Really amazing. So, the first question that I want to ask is, you know, thus far we've reviewed one resource—this very helpful guide that the National Health Law Program has produced, that's designed to be supportive of waiver comments in the commenting process. And I'm wondering if anyone here knows of any other resources that are available for helping people to comment on waivers, and if yes, if they are accessible, and in plain language, as well. And feel free to comment, no need to raise hands.

J **Jennifer Kucera** 1:01:47

This is Jennifer Kucera. I know there are different organizations that people have within their state, that can assist. Some of the organizations that we had reached out, to are the P&A systems. So your disability rights organization within your state, they may offer support. Sometimes The Arc—we have The Arc of Ohio—they may help as well. So if you have any disability coalitions, or any disability organizations that you are currently involved in, or you can even just do a Google search. There's a lot of times that they may not advertise that they offer assistance, but to me, it's worth an ask. It never hurts to ask. So, I would say to start with some of the disability organizations within your state to see if you can get some assistance.

S **Susan Koller** 1:02:44

And this is Susan. Obviously, I found the Olmstead Task Force, and Jennifer's group is very helpful in letting me know when comments are available. But, I mentioned the AUCD, and that every state generally has what's called the University Center for Excellence in Developmental Disabilities. And all those centers do a lot of work around comments on waivers and other things, so you can reach out to them. I would first go, maybe on the AUCD website and see if you can talk to someone about finding the center in your state. And a lot of those organizations, they'll collect—and I think Olmstead does this, as well—they'll collect a lot of people's comments and submit them all as one, because sometimes even submitting comments, if you don't have the right email address, can be difficult.

E **Elizabeth Edwards** 1:03:50

I would second all of that, and just say that oftentimes, your disability rights organization or your AUCD may be working in their own coalitions to submit comments, so they might be able to help you target what comments would be particularly helpful, for that commenting session. So they might say, yes, we're commenting and here's what we think would be helpful. You don't have to stick to what they say, for sure, but it may help you narrow down what would be most effective to comment about, at that given point in time.

L **Laura Bernas** 1:04:29

That's great. Thanks, everyone.

K **Kate Brady** 1:04:31

Can I add to that, Laura? Since we've jumped to that great second question about where folks should go. So you've mentioned already, a Protection and Advocacy (P&A) organization, a should go. So you've mentioned already, a Protection and Advocacy (P&A) organization, a coalition, a UCEDD, and in every state there is also a Developmental Disabilities Council. These three organizations are mandated by the Developmental Disabilities Bill of Rights Act, and so, you can always find these organizations. And as as Elizabeth mentioned, they may already be working in coalition to submit comments from their organizations, and might really find it very supportive to have the insight of your individual experiences. I can speak from experience in the DD Council that that's really, really, really valuable. So, you can indeed find your UCEDD on the AUCD site. You can find your Protection and Advocacy or disability rights organization on the NDRN (National Disability Rights Network) website, and you can find your DD Council on the NACDD website, which is the National Association of Developmental Disabilities. Also, in every state, there are statewide Independent Living Councils and Centers for Independent Living, and they are often also engaged in providing waiver comments, and you can find your Centers for Independent Living on the National Council for Independent Living website. So, those are lots of places, right? And it's great to hear all the panelist recommendations, both for how you do individual comments and how you might join others in commenting. And so, I'll jump to our next question for the panel. And we've hit on this a little bit, but curious about other than what we've already shared, are there things that are most challenging, from your perspective, about participating in the comment process?

**Jennifer Kucera** 1:07:08

For me, this is Jennifer Kucera, it was just really overwhelming, because I had never seen a waiver before. So, I think if I looked at a waiver a little bit earlier and known what I was in for, I would have been better prepared. So I would always suggest that, just like Elizabeth said, you can go to the CMS website and just get the general pattern for a waiver. You can find the waiver—if you can't find the waiver within your own state, the one that you might have, if you are on a waiver—you could always ask the department that houses the waiver. You can always question Medicaid, and see you know if they could point you in the direction of where the waiver is located. I would just suggest, even if there is no public comment period, that you look up your waiver. You may learn some things. It's good to see, good to experience that. And you know, it's always great, even if you don't want to do all this technical stuff, just think about the services that you receive. And if there's anything that you do not like about the services you receive, you can always just share that. So, you know, don't hesitate to add that in as the whole comment, or as part of your comments.

**Kate Brady** 1:08:30

Thank you, Jennifer. Other thoughts?

**Laura Bernas** 1:08:34

I was thinking, Jennifer, when you were speaking earlier, you kind of talked about all these different waivers, and then the different administering agencies, and who's responsible for them. And I think one of the things that we've heard a lot over the course of this project, is that often people don't even realize that they're on a waiver, or that that's how their services are coming to them. And so, I love what you said about, even when there isn't a comment period, kind of preparing yourself to be able to participate in this process that we have a right to, by just familiarizing oneself with, well, where are my services coming from? What are the different agencies that are inside of my state government that might have something to do with how I receive my services? And just getting more curious about that process, and learning a bit more on the basics of how this state system is set up and how it works, I think is so great to emphasize, because then, when this public comment period does happen, I feel like it can be less intimidating, because you kind of have that little on-ramp to what's actually going on in your state.

E **Elizabeth Edwards** 1:09:58

I would just add, based on what Jennifer said, CMS has all of the approved waivers on their website. So if you don't know where your state's waiver is, I wouldn't try to figure out where the state puts it on their website. Just go to CMS's website, it's all the most recent ones. And I think it can be really helpful. I'm not saying to go read your waiver, because nobody wants to read the whole waiver—but your case manager may not know the waiver as well as you want them to, and by reading the waiver or certain parts of it about services or limits, you may find that you're not being told about what waivers are available, or what services are available in your state. And you may find that there's services under a waiver that you're not being told about, or not being offered to you, or being told have limits that don't have limits. So, we often see where advocates call us and say, the waiver says this service exists, but we don't have it. And you actually can say, the waiver is supposed to say what the state has, and they're supposed to offer all services under a waiver to everybody who's in that waiver, and not sort of direct people one way or the other. And so, you may find that you're not being told about everything that's available under a waiver.

S **Susan Koller** 1:11:28

Elizabeth, this is Susan. Can I ask you a follow-up question? Where on the CMS website, would someone go to find [a waiver]? Because I even find that navigating CMS is difficult.

E **Elizabeth Edwards** 1:11:48

Yep, and we can make sure that this website is included in the follow-up materials. But I always, I have a bookmark on my web browser that has this CMS page, so I can just always jump to this page and find a state's waiver.

S **Susan Koller** 1:12:11

So if it was for a new person, would they just go on medicaid.gov, and Google waivers? Because we'll run down a rabbit hole, on that. Do I have a 1915(c), do I have this, do I have that?

E **Elizabeth Edwards** 1:12:25

Right. And one of the things that can be confusing—but there is, if you click on a given state, if you sort it by state, and you click on any of the documents, you can look to the waiver description that comes up, and that actually brings you to a page that describes everything the state has. In general, that's how that should work. But your person-centered plan should tell you what kind of waiver you have, if that's helpful, too.

**Susan Koller** 1:13:06

And I know everyone, when they sign up for waivers, they do get a copy of the plan and all that information, but even the plans are very cumbersome to read. But if you sign up for waiver, you get a document that shows you rights and where to go for information. All you have to do is figure out wherever you put it.

**Kate Brady** 1:13:33

This is so helpful, to be thinking about the ways people need to find and start out, in these different pathways that exist. We will absolutely make sure in the follow-up materials that this very important website is available. And, I think I'm hearing another thread here, which is that, we're also inviting you to begin wherever you can start. If that's with the website, that's good. If it's by asking your case manager, hey, what's this waiver called? That's fine! If, as Jennifer suggested, you want to write somebody that you know downtown, in the Medicaid office or in the Developmental Disabilities office, and you want to say, hey, I heard about comments. When's that going to happen? That's good, too. All manner of initiating, or you articulating how things are going for you and what needs you have that are unmet, is valuable and important, and is a part of the public record when you do it formally. Okay, let's move on to the next question.

**Laura Bernas** 1:14:51

Yeah, so we've touched on this a little bit, and this is a great lead-in. So our next question is, why is participating in this public comment process important? And I'd love to hear, you know, if you want to give an [answer] specific to your experience, that's great. And then also, you know, in general, why is our public participation and commenting important?

**Jennifer Kucera** 1:15:19

This is Jennifer Kucera. I would say that—because we as people with disabilities have, for so long, been told what we can and cannot do—that we do have power. We do literally have power. And the power is commenting on these waivers, on things that we do not like. The people that make the rules don't necessarily see how the, what I call "boots on the ground" is going, and without us that use the waiver speaking up, nothing is ever going to change in the way that we necessarily like. So I'd say that is the number one reason to get involved in this process. So, if you don't speak up, it may not happen. So use your words.

**Susan Koller** 1:16:12

This is Susan. I would echo completely what Jennifer said. And if you want a very personal example, I just found out, and this was probably one of the most important, if not the most important, reason I decided to try community living. I just found out in my second comments important, reason I decided to try community living. I just found out in my second comments go-around—I want another service dog, and I found out that certain parts of my service dog costs, and now covered by my waiver. So I was able to say, thank you so much for that. You know, that's very helpful. And I was also able to say, but it would even be more helpful if you would help pay for a fence—because that makes me even more independent—if you give me, if you can pay for part of the fence for the service dog, so I can have an area where I can take the dog to the bathroom myself. So that's a personal example, because that was the main reason I moved out of the nursing home again, was to get another puppy.

E

**Elizabeth Edwards** 1:17:35

I would just say that's a really good example. The more you get involved in this, and maybe start talking to advocates in other states, you may hear what waiver services they have. For example, thinking about Susan's example, certain states have service animal support services in their waiver. So you may say, I want that. Can you please add that? And this is what it needs to include, because this is an important part of community living. And the other part of that is, a reminder that—I think everybody knows this—but a waiver is supposed to be a feasible alternative to institutional living, which means it really should cover everything you need to live in the community, and not just exist, right? It should be covering everything you need to fully engage in the community. And I think to some extent, states have pared waivers back to just sort of being, what do you need to survive? And I think people with disabilities, as a community, are the only ones who can tell the state, what do you need to really be in the community, and enjoy yourselves? And what does a waiver need to do to help you, support you in that? And that's a really important piece, as Jennifer said. They need to hear from boots on the ground, and not just have high ideas of policy-level things about what should and shouldn't happen in a waiver. They need to hear how people experience life using waiver services.

L

**Laura Bernas** 1:19:12

I love this. I feel like I want to uplift two things. You know, I feel like a thread that I'm hearing is, if we don't share what our personal experiences are, if we don't actually talk to each other about what we're experiencing, what our services are like, what our experiences of advocating or getting involved in advocacy—we really don't know what's going on in other communities, or with other disabled people who are around us—and so it really can be so important, and so helpful and powerful, to really be open about what our experiences are, and actually have those conversations with each other. And the other thing I feel like I'm hearing, which is so great, Elizabeth, is that, you know, I do feel like there is a tendency to kind of do the minimum. Well, you know, this person is able to live at home, great, and it kind of stops there. But what we're really talking about is, how would any person want to live in in their community? And that all of those different opportunities and structures and things that are available to us, every single person has a right to those things, and that those types of things can be included in waiver services. Like providing fencing, so that people can actually go outside with their service animals, instead of needing someone else to do it for them. And to really think of those things just like anything else, that any other human being wants to have in their life, and not some sort of extravagance. I think sometimes what I hear back is like, oh, those are considered luxury items for disabled people, but the reality is that they're everyday items for everybody else. And so, really not feeling afraid or ashamed to ask for what we want, and to demand what we want, as well.

K **Kate Brady** 1:21:17

Yeah. Hear, hear. Thanks, Laura. I'm going to skip us to our last question, but it's a big one. And we'd love your thoughts on the other ways that people might get involved in having influence over, and on, the home and community-based service system design. So, what might people do before and beyond the waiver comment opportunity. We've heard a few tidbits already, but other thoughts?

J **Jennifer Kucera** 1:21:52

This is Jennifer. I'll start with a recent example. There's self-direction in some of our developmental disability waivers and in the aging waivers, but there were none in the Medicaid waivers that we had. And it was—well, there was, but it was very poorly run, poorly executed. So a bunch of disability advocates got together and just started having conversations about the self-direction program, with people that were either currently on it or wanted to be on it, or knew about what other states were doing. And we just started talking. And we ended up creating a document about things that we want to see in self-direction in Ohio, and we took it to Medicaid. And with the help of other partners, we were able to have a summit in Ohio that talked about all things—got everybody that had anything to do with self-direction in one space, for one day, and we are still continuing to better self-direction in Ohio. We are now working directly with our state Medicaid office. We meet them several times a month to build up the system that we, as people that receive home and community-based services, that we wanted to see in self-direction. So it is possible, you know, grouping together, banding together, like-minded individuals, to talk about the things that you do and do not like in your waiver. That is such a big thing, because we learn, right? So there may be a waiver that I'm on, that, say, Susan didn't know about. But then I tell her, and she's like, oh, I think that could work for me. Or vice versa. You never know. So talking with people that are in similar situations to yourself, is always such a great thing to do, and you uncover little things, you make connections, that take you to other places. So, that is definitely what I would suggest, is to meet with others in your state and to keep the conversation going.

S **Susan Koller** 1:23:58

And this is Susan. Once again, I echo what Jennifer said completely. But I would say also, look at the services your department that you're under, covers beyond your waivers. And I'm going to give a brief example of something I just did two days ago. DODD, which is Department of Developmental Disability, also has rules or requirements about housing services, and that's a big problem in Ohio. There's not enough accessible housing in enough places. I had to move an hour away from home just to find where I'm living now, which was kind of difficult. So I was able, just yesterday, or a couple of days ago, to comment on a housing rule. I didn't even know exactly what the rule was, to be honest, but I was able to give DODD my thoughts on housing for people with disabilities. Because if you don't have places to live in the community, home and community-based services don't necessarily—I mean, you can have all the services you want, but you also need that other component of housing to be happy, if that makes any sense.

K **Kate Brady** 1:25:25

Absolutely, yes. Thank you, Susan. You queued up a future possible webinar. So, I'd like to lift up the Beneficiary Advisory Councils, and Medicaid advisory committees. Somebody correct me if I've got the committee/council backwards, but, close enough. States will be—provided they move forward with implementation—will be recruiting for these advisory groups, and they may be valuable opportunities for people with disabilities to sit on those appointed councils and committees, to be in conversation about the design of the HCBS system. All right, so I think we owe our three panelists, Susan, Jennifer, and Elizabeth, a great thanks for such a dynamic and candid conversation. Thank you for reflecting on the actual experiences of your life, and sharing your expertise with us. We'll move now to close out the session, so I'll put the slides back up, and folks can go off camera. And we want to thank those viewing this session, and I didn't appropriately thank Laura for her astute and expert co-planning of this session. We will make the recording, the PowerPoint, and transcript available on the Grassroots Project website. Hopefully, if you're viewing this, you're able to scan the QR code on the screen, that will take you to where we'll upload these materials. And as we said at the opening, we'd be very, very happy to hear from you. We'd love for you to follow our newsletters and our YouTube channel and our social media. So please, get in touch with us via grassroots@hsri.org. Thank you to the interpreters for being here. We really appreciate your expert interpretation, both Jill and Sarah, thank you very much. And thank you to the viewers, and appreciate you joining this fourth Grassroots Project webinar. And hope you have a good rest of your day.