

BoggsCast Episode 15: Alison Barkoff

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JAIME ZAHID: Welcome to BoggsCast, where faculty and staff at The Boggs Center on Developmental Disabilities explore best practice, showcase success stories, and help listeners envision possibilities for innovation through interviews with state and national experts. Part of the Rutgers Robert Wood Johnson Medical School, The Boggs Center, is New Jersey's University Center for Excellence in Developmental Disabilities, and Leadership Education in Neurodevelopmental Disabilities program.

I'm Jaime Zahid, a Training and Consultation Specialist. In this episode, we'll be discussing the Home and Community Based Services Waiver with Alison Barkoff. Alison Barkoff was sworn in as Principal Deputy Administrator on January 20, 2021, and is currently serving as the Administration on Community Living's Acting Administrator and as the Acting Assistant Secretary for Aging.

A sibling of an adult brother with developmental disabilities, and a civil rights attorney, Alison is a lifelong advocate for community living, both professionally and personally, and has been at the forefront of national efforts to expand the Home and Community Based Services, HCBS, that make community living possible.

I'm joined by my colleague, Amanda Chirelli. Amanda is a young woman with firsthand lived experience with disability being born with cerebral palsy. She's a 2021 graduate of the New Jersey Partners in Policymaking program and has over 10 years' experience with public speaking and disability advocacy.

Amanda currently works for the Monmouth and Ocean County Independent Living Center, otherwise known as MOCEANS to those of us here in New Jersey, and is an Outreach Coordinator for the Education and Advocacy Department there.

AMANDA CHIRELLI: Today, I want to thank you for that introduction. And I want to thank Alison Barkoff for being on today and for interviewing you today. Thank you so much for having me on.

ALISON BARKOFF: I'm excited to have this conversation, Amanda and Jaime.

JAIME ZAHID: So Alison, I know I've already introduced you. But I'm hoping that you can expand on that introduction a little bit. And also, I'm always interested in knowing, what's your driving force that brought you here?

ALISON BARKOFF: Well, thanks, Jaime, Amanda, again, for having me on today. And that's an easy one for me. As you mentioned in my bio, I've really spent my entire life really working on disability rights

issues. And as the sibling of an incredible brother with developmental disabilities, I've really been part of the trajectory of how the world has changed for people with disabilities.

When Evan was first born, there were no options to have people live and stay in their own communities. At that time, we were told, like all families, to place Evan in an institution. And over the last 40 plus years alongside Evan, alongside my parents, alongside advocates from across the country, we have worked to make sure that people with disabilities have those same opportunities to be part of their family, to be part of their community. And a huge reason for that is the creation of Home and Community Based Services, what we'll be talking about today.

So that is really a huge part of what brings me to this. I'm really privileged to be in the federal government right now. But I've had a chance to work with The Boggs Center and many other advocates throughout my career. And it's really just an incredible time for our community to move forward on so many important priorities.

JAIME ZAHID: I can hear the passion in your voice. I hope that I sound like that when I do trainings and stuff. I hope that I sound like that. And I always think to myself, like, gosh, how lucky I am to do this type of work.

AMANDA CHIRELLI: Alison, thank you for that answer. And as a person with a disability, thank you for all you do for people with disabilities. But my question to you is, can you expand on the ACL a little bit and what you're currently working on as of now?

ALISON BARKOFF: Sure. So for people who aren't familiar, the Administration for Community Living is a federal agency within the US Department of Health and Human Services. And we really are the agency that focuses on, how do we make sure that every single person, regardless of age, regardless of type of disability, regardless of levels of support need, has the opportunities to be included in and fully participate in all aspects of community life?

So, it's an incredible opportunity, as Jaime mentioned in her introduction, not only do we administer a whole range of programs, actually both of you are part of networks that ACL funds. It sounds like Amanda, you work at a Center for Independent Living, and Jaime, you're at the University Center in Excellence in Developmental Disabilities. We fund a whole range of aging and disability networks that are in every single state and in most communities that provide everything from direct services to legal advocacy to the translation of research into practice, we support people with disabilities themselves, we provide a whole range of supports to caregivers.

And the goal of our work is to, as I said, make sure people have those opportunities, what is in my words, and the words of the Supreme Court, really a civil right that people have to be included. You can learn more about ACL at acl.gov, but in addition to the direct work we do, we also advise the US Secretary on Health and Human Services on disability and aging policy. And in that way, we work across all of HHS and with other federal agencies. Because as you both know from your work, disability is not siloed in any

one place. It's about access to community services. It's about inclusive education. It's about accessible and affordable housing. It's about transportation, all things we'll probably touch on today. But we really are that fulcrum and centerpiece on making sure people with disabilities and older adults are considered in all types of policies across HHS and the federal government.

AMANDA CHIRELLI: And Alison, I want to thank you for your answer. As a person with a disability, I really love what the ACL is doing and that you're trying to get us out in the community because I am a-- Jaime will tell you, I'm always out there doing something. So, I really do appreciate all your hard work. But my next question to you is, what is the HCBS Settings Final Rule and what are its origins? If you could expand on that a little bit more?

ALISON BARKOFF: Sure. And this is such a timely conversation because the HCBS Settings Rule is this really important rule that all of us, actually The Boggs Center, you've been an important part of this, our whole community for over a decade have been working on this.

This was a rule, so as we talked about, Home and Community Based Services are services that are funded by Medicaid that allow people with disabilities to live and participate in their community. They're an alternative to people receiving services in institutions. And there's a huge, huge demand for Home and Community Based Services. And while this was a program that was really cutting edge and started in the 1980s, it didn't have a lot of definition for a long time on, what does it mean to truly be home and community-based?

And I think people started to see that there could be settings that were quote unquote, "in the community" that still had characteristics that were very much like an institution where people maybe didn't have a lot of control over their own daily lives, or didn't have opportunities to go out in the community. Or they really interacted very rarely with anyone who didn't have a disability or paid staff.

So in 2014 with input from the community, tons of input, actually several years of input of people saying, what does it really mean to be home and community-based, the federal government put out this Rule defining Home and Community Based Services. And it had a transition period. So initially, five years. That was extended several times in large part because of COVID. And just on March 17 was the final implementation period. And at its core, and I know we're going to talk a little bit more about the specific elements, but this is about making sure that everyone who receives Home and Community Based Services has the benefits of community living. And it is also about some of the most basic civil and human rights that for too long have not really been a real part of many people with disabilities' lives.

So, this is a big sea change. And I think sometimes, the listeners who aren't a part of the disability community, when you hear about some of the things that are in the rule think you might be like, wow. Why is this a big deal? But I think when you really look at what people's lives have looked like, we are really moving things forward in a transformational way about self-determination, and control, and choice by people with disabilities.

This is truly about the fact that community living is a civil right, as the Supreme Court has said. We are really trying to make that real in the rules around the services that make community living possible.

JAIME ZAHID: Alison, as you were talking about that, it reminded me of a project that we're working on at The Boggs Center to educate people, professionals, individuals with disabilities, state workers, everybody, about what HCBS means to people with disabilities. And so we've been conducting interviews-- Amanda was actually part of some of our interviews-- conducting interviews where people with disabilities talk about what it looks like in their life when HCBS is upheld through their services.

And I know in some of our interviews, I'd preface the question with, I know this sounds like a really funny question, but, and for example, one of my questions is, can you snack when you want to at home? And when you're first looking at that question, it's odd. It's like, yeah. I live there. I should be able to snack. Why are you asking me that? But unfortunately, we've-- so many people with disabilities have lived in a service system where they've been told, no. You can't have cheese crackers right now.

ALISON BARKOFF: Yeah, I mean, truly, this rule is about really basic human rights, like you said. Things like, do you get to choose when you go to sleep? Or is there like a set schedule? Do you get to choose what you eat? Or do you have like a set meal time and a set menu? Do you get to choose who you live with? I mean, all of these things are truly, if you ask anyone in the world, what does it mean for something to be your own home? These are really basic things that everyone else takes for granted that we have had to put in a regulation.

And actually, it has taken providers a lot of work to change some of their, this is how we implement programs to being much more person-centered. And that's another piece that's really critical to this Rule, person-centered planning, which is not, oh, there's a program. Let us plunk you in it, but really moving to more individualized supports where it's driven by, what do you want to achieve? What are your goals? What are your strengths? And that's really, really important.

And then the other part of the Rule, so these basic human rights, these person-centered planning, and then the fact that people need to have opportunities to go out into the community, to participate in the community, is really, really important. And it is truly at its core what community living is about. So these are big, important things in this Rule. But we are really translating them at a service level and at an individual provider level.

JAIME ZAHID: Excellent. And I heard you say something so important that I try and make sure is clear when I train professionals about how it's not just about making sure people are physically present in the community. But are they a part of the community? Because it's so easy to just pick somebody up out of a group home, out of a developmental center, and put them in the park. But are they really part of what's going on in the park? Are they making relationships in the park? Do people know who they are? Would people notice if they're missing from a particular event?

I'm glad you touched on that.

ALISON BARKOFF: Yeah, and Jaime, I have to say, that's so important. Sometimes people have this worldview like, oh, is it safe for people to go out in the community? I am sure in every training, you talk about this. But the number-one most important way to keep people safe is to have people who are not paid to know and care about them, but to have people who know them, they are the-- those are the people who will notice when something is wrong. Will, like you say, notice if someone is missing. And that is the number-one most important way we can keep people safe, having them have natural relationships with people that care about them. And it is-- you are right. It is not just, we're going to go to the bowling alley, and it's disability hour at the bowling alley, but building those relationships and helping people.

In fact, the better we do person-centered planning, the better we build these natural relationships, probably the less formal services people need. And that is a sign of success too.

JAIME ZAHID: Yes. Absolutely. Can you expand on any of the particular elements of the Rule? And tell our listeners a little bit about how it should be impacting everyday life for people with disabilities. Why is this so important? Just in case we missed anything there.

ALISON BARKOFF: Yeah, so I think I hit on the major components. I will say that The Boggs Center put together, when the Rule came out, when stakeholders were starting to engage. As I mentioned, states had a number of years to implement this. And a really critical part of the Rule was that people who are most impacted, people receiving services, their families, and of course providers had opportunities to work with the state to give a public comment on the plans.

And so, that's where we really started to work on issues to make sure, in plain language, in words that were very accessible, helping make sure people understood you now have rights under this Rule. And so, truly for people who may be living in settings like a group home where some of these rules that might have been in place in your setting that don't comply with the HCBS Settings Rule, you should start seeing, you should have already seen, some of these changes that really give you more control and more choice.

And I want to mention, it's not just these basic things we're talking about, but things like people having control over their own financial resources, freedom from coercion, or restraint, people being able to have a choice of what services they want, and who provides them.

In addition, so many systems, and again, it's really historical from where we started with disability services, which were mostly places for people with disabilities, things like group homes or day programs, the Rule requires that people have a choice to receive services in settings that are not disability specific.

So what does that mean? Instead of living in a group home, people need to be offered the option to live in their own apartment and get in-home support, being able to probably self-direct, and your services, and be able to hire a family member, or someone that you know.

On the day service side, traditionally, there have been either sheltered employment programs, or day services. And this really is changing the options that are being offered in a state. So, people being able to work in a typical workplace with employment supports, instead of going to a place that is only people with disabilities.

So hopefully, people have seen really over the last several years is the state of New Jersey, and states across the country have been implementing this, these changes in their life, the changes in what they're being offered.

And at the same time, I want to say there have been delays in implementing this rule because of COVID. So much got put on the back burner. So much changed because of COVID.

COVID shone a light in general on how critical helping people live in their own homes and be in the community instead of in congregate or institutional settings is. We saw a huge number, over a third of deaths during COVID, happened in institutional and congregate settings. Of course, that makes sense. People are together. There wasn't a way really to isolate and to separate people. And so, I always talk about community living as a civil right. But in COVID, we saw it is literally a matter of life and death.

And what it did is truly create this unprecedented urgency, and demand, and visibility about the importance of expanding Home and Community Based Services. I really think COVID gave this momentum.

At HHS, when people were asking, should we extend the rule one more time, and give states more time, I think COVID is what made us say, these basic rights, people have been waiting a very long time. We need to make sure they are real for people now. We are not extending that.

States have an option right now. They have to get these basic rights in place by March 17. That was a requirement. But for things that were impacted by the public health emergency, or the direct care workforce crisis that's really come out of the public health emergency, states are able to work with the Centers for Medicare and Medicaid Services, that's the agency that's over the Medicaid program, and come up with a time-limited, very concrete plan, on these are the things that we have left to do to really implement the Rule as we're coming out of the public health emergency.

So hopefully, everyone who's listening and receiving services has both seen some big changes in their own lives, and how they are receiving services over the last couple years. And, if there are things I'm talking about and you're saying, oh, it's not really quite there for me yet, know that there's more work to be done. We're not fully there yet. But we've come a long way.

JAIME ZAHID: We sure have. As you're talking I'm thinking about-- and I feel like I've thought about this before. But you've really brought it to light. The importance of making sure that people with disabilities and their families are aware of the Rule, and what it means for their everyday life when they wake up in the morning. It's a huge responsibility on us to make sure that they-- that they've really understand it.

ALISON BARKOFF: Yeah, it is, Jaime. And something that we're doing with both Amanda and Jaime, your networks, is we put a lot of time and energy into engaging stakeholders early in the Rule so they could comment as states were developing plans. Now we've kind of pivoted and we've said, we really need to make sure people know their rights. And we've pulled together actually both of your national associations are part of this.

At ACL, we're really putting our money where our mouth is. And we're saying, people who are most impacted need to know their rights. They need to have a voice. And this is not just, oh, you do the Rule one time and on March 17, it's all done. This is the new rules of the road. This is ongoing. We need to make sure people are-- know their rights, they continue to be engaged, every opportunity that the state has on, we're making changes to our HCBS program, or we're renewing a waiver, any of those kinds of things. People need to know how to engage.

So at ACL, we have invested in leveraging our networks to make sure the people that they work with, or people that they serve, people with disabilities, and families, and providers know how to continue to be engaged. It is really critical.

And so Jamie, dust off that incredible document that y'all put together explaining in just very concrete ways what the Rule means, and a checklist of, am I seeing this in my own life? Because we need to make sure everyone knows about that.

And as part of what states had to do by March 17th, every single state has to share with people receiving services, how do you file a complaint if something's not happening in your own life? So, in New Jersey, the state of New Jersey has to say, this is who you call, whether it's your case manager, or the state Medicaid agency, or the state DB agency. It's different in different states. But people need to know, these are rights, and who you can reach out to if it's not happening in your own life.

JAIME ZAHID: Absolutely.

AMANDA CHIRELLI: Alison, thank you for that answer because I-- there's a lot of people with disabilities that I'm afraid to say they don't know what the HCBS Rule is. So, me as a advocate, I try to push for what that Rule really is and how important it really is. Thank you for that.

What can people like me with disabilities, and their families, do to advocate for the rights under the HCBS Settings Rule, Final Settings Rule?

ALISON BARKOFF: Yeah, so there is no one who knows better about what is working and not working in their state disability service system than people with disabilities who are receiving services. And it is so critical that those voices are heard as the Rule is being implemented and in broader policy around HCBS.

As someone who was involved-- actually in my last stint in the government a decade ago—in helping develop this Rule, input from people with disabilities, and other people receiving services, is not just a nice thing. It's not just an afterthought. It was actually a requirement of the Rule. The state had to go out and get public comment. And of course, if you want something to work, if you want something to be real, those voices are really, really important.

Involving stakeholders in every step, there's like the floor of, yes who have to get people's comment. But really some of the best practices we saw from states were creating working groups and implementation councils that included people receiving services and their families. And that is what really helps make a better quality of services, and more responsive service systems.

As I mentioned to you, ACL is working with national advocacy organizations. And we put funding towards this to help their state members engage grassroots at the local level. So we're working with the Protection and Advocacy networks. We're working with the UCEDDs. We're working with the Developmental Disabilities Councils. We're working with the Centers for Independent Living. And most importantly, we have brought in self-advocacy organizations like the Autistic Self Advocacy Network and the Self Advocacy Resource and Technical Assistance Center, and state self-advocacy chapters to really, really make sure all of those voices are at the table and that they are working together.

And our goal for this year, we really focused on the Settings Rule over the last year. But we know HCBS policy is broader than just the Settings Rule. So we are going to not only continue working with stakeholders on a how to on implementation of the Settings Rule, but making sure people understand how to engage in HCBS policies across the board, how to engage in monitoring of their systems, and how to really make sure that there is feedback from participant stakeholders. So we're really excited about taking this even bigger with the partnership of networks like you all.

AMANDA CHIRELLI: And thank you for that answer, Alison, and your wealth of knowledge as always.

As you know, every advocate has something that they're passionate about. And one of the things I'm passionate about in channeling through my advocacy as of now is transportation. And as you know, transportation in New Jersey is a hot topic in the disability community, especially for those of us with mobility barriers.

What can HCBS do to move the issue along for people in New Jersey? And what could I do as an advocate?

ALISON BARKOFF: Great. It's a great question. And it's so timely.

As you mentioned, if people don't have access to transportation, they're not going to be able to go out in the community and participate. And so it really is a huge barrier, a huge thing that we need to think about. And it's part of the conversations that many states are having when we're looking at the rules,

requirements of people receiving HCBS should have access to the broader community to the same degree as people without disabilities.

Let me just mention a few other things kind of outside of the Settings Rule. Because number one, as people know, there was a huge infrastructure bill that has recently been passed by Congress. It is the biggest infusion of funding into transportation in decades. And it is a really important time for state advocates to get engaged.

A great thing about that rule is that it requires accessibility as new projects are rolling out. And in fact, in that bill, there were some specific pots of money to go to make, for example, rail stations that existed before the Americans with Disabilities Act. They have different rules around accessibility of new stations versus existing stations. And parentheses, the ADA is 32 years old. But in places like New Jersey where you probably had train stations that were built in the '60s, '70s, or '80s, they may be less accessible.

So one of the great things in the infrastructure bill is funding to help states and local government retrofit and make some of the existing infrastructure accessible.

And then, all of this new money to go into transportation. It's really exciting. And actually, the Department of Transportation has a disability advisor who works with the secretary and across all of the Department of Transportation. And so that's been a really great opportunity.

I will also mention that at ACL, as I said, we really work across the federal government. And one of the partnerships that we have is we work together with the Department of Transportation on a National Transportation Accessibility Center that really focuses on expanding accessible transportation for people with disabilities and older adults, making sure that we are really lifting up accessibility strategies, and mobility on demand transportation systems, and inclusive strategies.

And so we have information about that that we can share with you. This is really a national resource and a technical assistance center where we can work with stakeholders across the country. And if you're interested in more information about that, you can go to nadtc.org and get more information there.

And you are so right, Amanda. We want to give lots of tools to advocates like you to make sure that accessible and affordable transportation is there for people with disabilities. It's a great thing to put your energy into and an awesome time to be doing it.

AMANDA CHIRELLI: Well, Alison, I will be checking out that resource for sure. And I will be sending it to my colleagues at MOCEANS and any other advocacy avenue that I have.

Alison, in closing, I wanted to ask, what are some of your closing thoughts on what people like me, and other advocates, can do in their career to enhance their advocacy? And how could I get more involved with ACL?

ALISON BARKOFF: Yeah, that's great. So Amanda, as we were jumping on, you mentioned Partners in Policymaking. And it was actually, you said, the place where you would first met me. And I think that's the context I had met Jaime, which is such an amazing program. And so for anyone who's listening who's interested in learning how to be a really incredible advocate, and how does Congress work? And how does your state government work? And what are different ways you can get involved?

That is really an awesome way for people to really get the nuts and bolts on advocacy. So Partners in Policymaking, I know Boggs offers that. And that is one way that's really, really great.

There's so much advocacy that happens at the state level. And for many of you, and Amanda, and Jaime probably know the particular organizations in New Jersey. There's so many disability advocacy opportunities.

And I'd say get involved. Find the thing that you're passionate about. I love, Amanda, hearing about the work that you're doing around accessible transportation. It sounds like there's an advocacy group that you're working with that probably has brought together a lot of people who care about that issue.

Pick the thing that gets you motivated. Pick the thing that's the biggest barrier in your life and find other people who want to work on that. And start chipping away at it.

Now I think for me, it's like always finding those peers, always finding that community. I just find the disability community and the advocacy that's there, it's so rich. There's so many opportunities. There's so many organizations. I am sure that The Boggs Center can help connect people with, what is the thing that you're really interested in being engaged in?

At ACL, I will say we have lots of opportunities. We always share those publicly. So for anyone who's interested, please sign up. You can go to acl.gov and sign up for our listserv. We send things out every week. Oh, there's a rule that came out from the federal government. This is what it means to people with disabilities and older adults. And it's out for public comment. Or sometimes, we have advisory committees, or work that we're doing. And we're seeking people with lived experience to be part of our work. And that's where we share it. So there's so many different ways to get involved.

Find the thing you're passionate about. Jump in, whether it's at the federal level, or the state level, or the local level. But I'll just end by saying this. Know your voice matters. Sometimes I find people are like, but I am not a subject matter expert. And when I say to anyone who themselves is a person with a disability, or as a family member is receiving services, you are an expert because of your experience. Bring that to the table. Don't be intimidated.

And your voice is critical to making sure the work that we're doing around the HCBS Settings Rule really is translated into reality, that it lives up to its promise. And it's just-- it's really, really critical that people get engaged and stay involved.

AMANDA CHIRELLI: I definitely agree with your answer. I'm really involved and I'm definitely going to look onto acl.gov in the future and pass it along to some of my colleagues, like I said. And I always love to get on webinars and learn a few things. So I will definitely be more involved. That's for sure.

JAIME ZAHID: And Alison, of course, yes. We're more than happy for anybody who's listening to help them connect to any advocacy opportunities that they're interested in.

And you were talking about people being hesitant to advocate because maybe they're not an expert. Through our work, especially through Partners, where I'm always emphasizing to people that advocacy doesn't have to be putting on a suit and tie, and going down to DC or to Trenton.

Advocacy can simply be going into ShopRite and saying, hey. You've made the end cap so big that I can't get my wheelchair around. And I can't reach that can of beans that I'd really like to grab. That right there is advocacy. And I think that's so important for people to understand that. And you might have influenced just one person to realize that, oh, I made this area inaccessible for somebody. But then that's going to have a ripple effect. And next time, they see something else that's inaccessible, perhaps, they're going to act on that.

So thank you so much, Alison, for your time and expertise today. Of course, we look forward to hearing more from you in the future through whatever avenues that might be. And Amanda, thank you so much for your time and your experience that you lent to the podcast today.

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