

REALTIME FILE

AUCD-MANAGING STAFF AND VOLUNTEERS WITH GUARDIANS
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>> KATIE JOHNSON: It's so great to have a number of you join, especially Matt, I know that I extended a special invite to you to join in. Welcome to the Admin Essentials Series. I am Katie, I work for our UCEDD resource team, and we're really excited to have you join us for this event. This is a roundtable discussion, so we're going to talk a little bit together. It will be hopefully really interactive and a chance for people to share resources and different ideas.

Our topic is on managing staff and volunteers who are under guardianship. The history of this discussion topic came from a question from our network about other UCEDD policies, so we wanted to create this kind of iteration of our series to address the topic and see what people are doing around it and to share some resources.

We've invited Cathy Costanzo and Anna Krieger from the Center For Public Representation to kind of inform our discussion on the topic, since they're both content experts on guardianship, kind of at the national level.

So that everyone knows that policies vary from state to state, so it's really hard to be an expert on guardianship for everyone. But our hope is that together, we can kind of share resources and promising practices as we trouble-shoot through how to support and manage staffs who are in guardianship situations.

This event is being recorded, as I said. Following the event, a tip sheet will be made to kind of capture what we talked about and will be disseminated alongside the recording. We're asking that people can turn their cameras on. We have a really small group today, so if you're able, we'd love to see your faces.

We're going to have people share their experiences and what they're hoping to get from the event as well. Thanks. I know it's early in Guam, isn't it? Appreciate you always being here, even though I know it's early.

Thanks, Michelle.

And our hope is when you're not speaking, you can keep your audio, your microphone on silent -- sorry. Keep yourself muted to prevent background noise. Because we're a small group, our hope is you can just jump right in as we get to the roundtable part. And we really want this space to work for you.

So whatever questions you have, bring them to the table, we're ready to have a lively discussion. There's going to be a short evaluation survey with all of our events. Put it in the chat box once we're finished and we hope you can give us suggestions for future topics, because it's requests from people in our network that make events like this happen.

So, with that, I'm wondering if we can introduce ourselves and say why are you here and what are you hoping to learn from our session.

>> I can start. Hi, everyone. It's nice to see you. My name is Matt Gianino. I serve as the associate director on the Institute of Disability at the University of New Hampshire. Katie, thanks for the invitation to join.

I'm here more to learn than anything else. We've had a couple of instances where guardianship implications have come into play, and it was hard for us to really kind of find resources and best practice around this, so I'm hoping that today we can lead with some new information and new guidelines around how best to support our staff and volunteers.

In our case, it was actually a member of our consumer advisory council and how best to support that member in the important work that they do with us. Glad to be here.

>> Hi, everyone. My name is Michelle. I'm the associate director here at the University of Guam Cedars. I'm here to learn. I just completed my first year with UOG Cedars. So, yeah, here to learn more about it. We don't have currently any volunteers or any employee who is under guardianship.

So hopefully when we do, then I'll be prepared.

>> KATIE JOHNSON: Thanks, Michelle. I see, Jessica, you're on the line. Would you like to say a little bit about what you're hoping to learn?

>> Hi. Can you guys hear me? This is Jesse Keenoy. I'm with ICI. I work in the State of Missouri providing technical assistance and training to service providers and the issue of guardianship comes up frequently, so I'm trying to learn as well, as other people said, and take information back to my team and to the providers that we work with.

I'm trying to turn my camera on, but my Wi-Fi is down in my house, so I'm joining you by phone.

>> KATIE JOHNSON: That is okay. Yes. The last six months, I feel you with the tech issues. But I'm glad you're here, and I hope that we can have helpful resources for why you're joining.

Kathy and Anna, do you want to introduce yourself as well?

>> ANNA KRIEGER: Hi, everyone. It's so nice to see you. I can't believe we're meeting virtually with folks from right here in New England and Guam. I mean, technology is kind of amazing sometimes. So we're so excited for the conversation today.

My name is Anna Krieger. I'm a senior attorney with the Center for Public Representation. Cathy is going to go into a little bit more about what Center for Public Representation is all about and kind of our different values and interests that brought us here today to talk to you.

But mostly, I'm just really passionate about empowering people with disabilities and making sure that people's legal rights are being protected and respected. So I think we're going to have a great conversation with that as part of our umbrella or background today.

>> CATHY COSTANZO: Hi there. I'm Cathy Costanzo. I'm the executive director of the Center for Public Representation. We call ourselves CPR these days. And we are a public interest law firm, although we do a lot around policy work as well. We have -- our main offices are in Massachusetts in the eastern part of the state, as well as in the western part of the state, where we got our start in the Northampton area. But we have an office in D.C. that does policy work.

We have a lone attorney working out of New York City at the moment. CPR has been around at least the last 40 years. I kind of lost count. We really see the focus of our work being to empower people with disabilities, to create opportunities for people to be full participants in their lives and in the communities in which they live.

And I guess for those people who aren't yet communities to try to see that that happens for them. So we do a lot of our work through litigation, but we also do, as I said, working on national policy issues around settings, the Affordable Care Act, and we're up to our eyeballs in it at the moment.

We have an interest -- for the last ten years, CPR has been really focused on working in the context of the employment area. We brought the Lane case out in Oregon, this was a case to challenge the use of sheltered workshops as violating the Americans with Disabilities Act, and creating a set of other opportunities for people to work in integrated competitive employment in the community.

So I guess the person from DCU isn't yet on, but we worked with Paul from DCU as one of our experts in that case.

Our experience there has been that lots of people who have guardians are working competitively in the community, so we thought we can kind of build on that and talk a little bit about that experience as well.

We also for the last five or six years have been focused on supported decision making, which is, as many of you may know, an alternative to guardianship, for people who may need supports in making decisions, but not necessarily need to lose their full voice and legal identity by having a guardian imposed.

So Anna and myself and a couple of other staff in the office have spent a lot of time developing different models for supported decision-making, and supporting individuals and their families and the people who work with them to support them, and the people that they choose to have be part of their network, so function very effectively and to live full lives without guardians.

So this question then that came up around today's topic was one that intersected with a lot of our interests and experiences, and hopefully we have some things that we can contribute on both of those things. So we look forward to the conversation.

Anna?

>> ANNA KRIEGER: Should you just take it from here, Katie?

>> KATIE JOHNSON: That's great.

>> ANNA KRIEGER: So I think we have some different things we can go over. We'll give you kind of just a quick overview of our thoughts about

working and guardianship together, and then I think really quickly, you know, let's turn this into a conversation about the particular scenarios that you all have encountered, and/or hypotheticals you're wondering about, and we can try to talk through and think about those.

So I think the first point we really want to emphasize is just the idea that there is a long and rich history of people with disabilities under guardianship working, in paid employment, in real community jobs.

And obviously central to our work promoting competitive integrated employment, connected to sheltered workshops, we've seen that. We've seen it time and time again that there's no correlation in our minds about whether someone should be under guardianship and whether or not they're capable of working.

I think when you really drill down on that, the reason there are statistics out there that show accurately, I think, that when you're under guardianship, you're less likely to work. We think if you unpack that and think about it, it really comes down to a series of biases or assumptions about people with disabilities.

Particularly people under guardianship, where someone might not know or understand a lot about what a guardianship is or means, might think that means they're incapable of working or incapable of being in community, and we obviously just believe that that's wrong, and a false understanding.

And so, I think that those biases are a part of what contributes to the lower rate of people working under guardianship.

And the other dynamic we think contributes to it likely is guardians who, it's not just employers who might have some of those biases, but guardians as well who might have just a vision of the person who's under guardianship that is not a real reflection of that person's capabilities.

And so as a result, the person gets fewer opportunities to explore the possibility of work and all of that. So I think we just really feel it's important when having this conversation to start from a place with -- as a shared value that people with disabilities are capable of working in real community jobs and a guardianship should not be an impediment to that.

There might be some, you know, glitches, problems, or challenges that come up, but they're barriers that can be overcome. It wouldn't be a red flag or anything like that. It's more like a maze you might have to find your way through a little bit, but it's not a long maze, it's a short maze. That's kind of our overall message.

Cathy, did you want to talk about -- or do people want to respond or challenge us on any of this? We have firm views and we're happy to be challenged on them.

>> I think that you'll find you're in good company today.

>> ANNA KRIEGER: Yeah.

>> CATHY COSTANZO: As we're going, if something occurs to you or you just want to ask about it as we're going, you should definitely -- it's a small enough group that we'll have more than enough time to get through what we have prepared and hopefully a lot more conversation that can then follow.

So if there's not any questions at the moment, I'll continue then. There's nothing about guardianship that really precludes someone from working. So that's the first thing. There's nothing legally about it, practically there may

be some things to have to sort through.

You know, there's this idea of what a guardianship does. It either protects someone, in certain ways it does do that, but it also restricts certain rights that people have. You know, the right to decide things for themselves, the right to make some basic fundamental decisions. So depending on the nature of the guardianship, you can lose all sorts of rights, or you can have just certain of your rights restricted.

Now, one of the things that's really interesting is that -- and we'll be talking about this, but across the country, 63% of the states, of state guardianship laws actually encourage guardians to encourage the development of the maximum self-reliance and independence of the person under guardianship.

And so, when you really think about that, and think about, you know, work as one manifestation of that, it really becomes quite clear that, you know, just because someone may be incapable of handling, like, if they inherited money, let's just take an example of somebody who may have had a family member die, may have inherited a certain amount of assets, or have a trust set up for them, or some money that they've gotten from their family.

They may not be capable of managing investment decisions around that money. And so they may need guardianship around financial matters, but they may still be able to make certain basic decisions.

And certainly, even if they needed help in certain areas or even a bunch of areas, that doesn't mean that they're incapable of holding down a job, and again, under those guardianship laws, that the guardian should not be serving as an impediment to that.

Now, we recognize that sometimes guardians can be impediments to those things, and then we can talk about a little bit later what to do in those situations.

But, you know, I think just to understand that working and holding a job or participating as a volunteer in something that has a lot of status that is -- gives someone a sense of connection and -- like a valued social role in our culture, is something that we should see as desirable and consistent with many of these guardianship statutes and arrangements.

And by statutes, I mean laws, okay? Statutory law.

>> ANNA KRIEGER: We were just going to make sure we all kind of had a common understanding of what a guardianship is. You know, which I think probably we all do, but it's probably worth just taking a moment to step back and say that.

Because I think we throw it around that it can mean different things. Really, at its basic level, a guardianship is just when a court is finding that based on whatever the standards are in state law, a person lacks capacity to make certain decisions. And it can be all of those decisions, it can be some of those decisions, and we can get into the different types of guardianships in a minute.

But basically, the Court makes that decision about some of all of the types of possible decisions that are at issue, and decides, yes, this person does not have the capacity legally to make decisions on these issues, and then there's a court order that results in paperwork, basically, that says this person is under guardianship, here is the list of areas that this guardian is

covering.

So I think sometimes it's easy to forget that there's actually a court order, that it's not just, you know, an automatic process, all of those things. So I'm sure we all have that understanding. But we thought it was worth sort of stating that explicitly.

>> CATHY COSTANZO: The long guardianship is really going to vary from state to state. So we can tell you what is the we could talk about trends nationally, but we could not be able to speak to each guardianship arrangement in your state. Or your territory. So I think one of the things that --

One of the things that CPR does is provide training and technical assistance to the protection and advocacy network. So for all of the various states and territories in the country and beyond.

And in doing that, we recognize that each state has certain ways of doing things and certain statutes that are not identical to their neighboring states or even a state across the country. So, guardianship statutes are one of those places where there's a great variation. There are some common themes.

But we think it's really important for you to become familiar with what the law in your state requires, whether you're one of those states that are in that 63%, independence, self-determination, and so on is encouraged for someone under guardianship. And even if you're not, it still seems like it would be a good practice for a guardian to be engaged in those behaviors and trying to support the individual in that way.

I think it gets very complicated, and I'm sure -- I don't know about each of your jurisdictions, but let me just say in Massachusetts, we unfortunately have a lot of what are called corporate guardians. They are sometimes guardian for -- or even private attorneys who serve in that role as guardian. Sometimes will have 100 wards that they're responsible for. And so the idea that they were going to have very individualized relationships with each of the individuals they're responsible for.

And actually be encouraging and fostering that kind of independence and supporting that and ensuring that the person is gaining additional skills and so on through life is probably not very real given those arrangements.

So, you know, I think we have to recognize. And some of those corporate guardians in Massachusetts are fairly progressive and some of them are awful. And so it really just depends on who the individual you're going to be coming into contact with who may be wanting a job with you or to be working with you on a project or so on or volunteering even, who their guardian is. Because that's not just the statute, but actually in your state.

But who that individual is, is going to be another consideration.

One of the things that's come up is -- so if you're -- there's nothing -- so, again, depending on what the law in your state is, and what the actual guardianship order says, it may be that the individual under guardianship retains the ability to enter into a contract, such as an employment contract.

Or to agree to be a volunteer or to do the -- and so for a lot of your projects I would assume that the same kind of -- if it's a contract for employment, the person will have papers that they have to sign. And employment papers, about their benefits and so on and so forth.

So one thing to know is whether a person's guardianship extends to

cover that. If so, whether the guardian is willing to delegate, their ability to assign those things, or whether the guardian needs to be involved in them, or having the individual and the guardian assign them together, or both to sign off on them.

I think for individuals under guardianship, it's very important that somebody be explaining all this to the individual in a way that they can understand it. And so, hopefully, that happens through the guardian, but also if you're offering a person a position of some sort, that you're also taking the time to do that as well.

>> I was just going to interject. It seems timely to ask a question. This is really helpful information, Cathy. I feel like there's something that needs to precede the kinds of conversations that you're describing right now.

Particularly where the potential relationship is not as formal as employment, say, in an advisory capacity.

Our best practices around initiating, if, in fact, there is a guardianship just to begin with, and what are we legally bound to from an HR perspective, there are specific guidelines around inquiries around health and disability and things of that nature.

And I want to just understand, how do you best initiate the conversation related to guardianship before we get into the details of what the guardianship design, restrictions, language looks like?

>> CATHY COSTANZO: Let me say I'm not sure, so we can talk about it. Let's just kind of talk through the nuance of this. Jessica, we're working with ICI on a grant right now, where 75% of the individuals that are going to form an advisory group for the grant have to be people with intellectual disabilities. And, you know, that's a great thing.

But I think we're going to be facing exactly the same question, like do we just invite the person, do we have to invite the person, but ask permission? How do you know if you have to ask permission of someone other than the individual who that needs to be.

And I think we need to just try to have those conversations in ways that are really sensitive to the individual. But I think it's fair to say, you know, as you're getting to know someone, that we would like to think about -- we would like to get to work with you more, and we would like to know if in doing that we need to -- whether you have a guardian and whether we need to include that person in the conversation. I think that might be one way of asking it without making the person feel badly. Or we could say a lot of the people we work with from time to time have had guardians.

And it's important if you have one that we know who that is so that we can figure out with you if we need to include them in the conversation.

I don't think it would be to not continue the conversation with the individual, but really to think about who else might need to be included, either in that same conversation or in a separate one.

>> ANNA KRIEGER: Yeah, I think my instinct is similar. My main message would be not to create a problem where there isn't one.

So I think there's not -- particularly for someone in a volunteer capacity, there's not going to be something in a guardianship that says this person is restricted from, you know, serving on a board, or associating with certain people. That's not the kind of things that are going to be coming up in a guardianship order.

It depends on the state obviously, but an order is going to contain things like finances or healthcare decisions or those kind of things.

So my sort of gut feeling is similar to Cathy's, which is, if you have someone who is interested in serving an advisory council of some kind or other, that it's about, you know, getting to know the person and unless the guardian is raising some kind of issue, I don't really think that guardianship creates any barrier, particularly to just serving on an advisory council.

I think framing everything in terms of empowerment and, you know, making sure that the person understands that any inquiry you are making about a guardianship isn't that you want to bypass them and go to the guardian, you know, to subvert that person's voice, I think is really -- is important and that's implicit to what Cathy was describing.

>> CATHY COSTANZO: Yeah. I think, though, in the grant that I was just saying that we're doing with ICI, we're going to be dealing with youth between the ages of 14 and 26, is the way that the federal grant has defined the population of people.

So obviously, for -- in different states, people reach the age of majority at a different age. So, in Massachusetts, if you're 18, basically, unless a guardian has been appointed, you have the legal voice to make decisions for yourself. But it really varies according to each state at what age that happens. So at least in state -- so, you know, as I was just sitting listening to your answer, and I was thinking, yeah.

But think about this for some of the youth that we're going to try to get to be on our advisory council for this grant. Some of them are going to be between the ages of 14 and whatever is the age of majority in their state.

Their parent/guardian needs to -- somebody needs to probably be at least accepting of it, if not like excited about it, you know?

So those are just certain realities. I think there's a way to still involve the person and work with a person and talk to the guardian if that's what's needed. It may not be needed. It may be enough for the person to speak to their parent or their guardian and to get a green light to go right ahead.

But to the extent that it isn't, that's where we all have our work cut out for us.

>> ANNA KRIEGER: I think the challenge is just really making sure you're applying the same standards to someone you're working with who has a disability and who doesn't. So if, for instance, you've got an advisory council that was just youth, not youth with disabilities, would you be asking them to get parental permission before joining?

If yes, I think you apply the same standard to a council that includes people with disabilities. So it's just about -- I think sometimes that's a helpful framework to apply when you're thinking about these things, you know, making -- to make sure that you're both doing things the right way and sending the right message to people you're working with about how you value their voice and their independence.

>> CATHY COSTANZO: Matt, it might be that you could just say, you know, in the event that you have a guardian, you know, would be helpful for you to talk with them about this, and if we need to, you should let us know.

And that might be a way to sort of raise this subject without necessarily making the person have to tell you something that they may not be prepared or wanting to talk about in the same way that you can -- you

know, you have to stay away from certain other subjects in HR context.

>> ANNA KRIEGER: And I think it's tricky, just to be really candid, I think there are some people who would rightfully be offended if they -- you know, you assumed that they had a guardian and they didn't.

And so how you approach that is important. You're sending an important message in the way you ask it. So, like, another -- I'm just thinking out loud here, another way you could consider approaching it would be to talk to the person and say, is there anyone -- we want to make sure this is an accessible process, that your participation meets all of your needs, is there any accommodation you need, are there any supporters that help you that understand how you communicate well.

You know, just giving some examples of the types of accommodations you've made for people in the past. And you could include something connected to a guardian so that that issue is sort of raised.

But I don't think it's necessarily taboo to raise it in a direct way, but I think you -- like Kathy was saying, I forget your exact language, but it was very good in terms of raising it without assuming anything about the person, because I think that's really important.

>> KATIE JOHNSON: Matt, I'm wondering where you are -- I know that the original request was a while back. So I'm wondering how this has played out in your situation and kind of what steps you've taken. Just because I think it might be helpful for others in the network through your example if you are able to share.

>> Unfortunately, I can't share a lot because it's sensitive in nature. I will say a couple of things. One is that for us, guardianship would never represent a barrier. Perhaps the exact opposite. 100% of our consumer advisory councils are either individuals who experience a disability or a family member of an individual with a disability.

So this is -- so this would not be a barrier in any way.

I think where we kind of have struggled is, one, identifying individuals that we're working with, particularly who are under volunteer status, whether or not they have a guardianship at the outset.

And secondly, understanding that the details that pertain to their role as an advisory member, that would be helpful for us to know.

The third thing I would say to your question, Katie, is where -- you know, usually, this is a non-factor. Where it came into play for us is actually through a process of mediation and conflict resolution. And if and when it is necessary and appropriate to bring a guardian into that conversation.

So we're not talking about executing a contract or legal status, but because there was an issue that arose that was sensitive in nature, it did require some conflict management and mediation.

What was our responsibility as it pertains to dealing with that with a volunteer with a guardian.

>> ANNA KRIEGER: Was it the idea that the guardian could be helpful, or that the guardian -- you're concerned that the guardian could be helpful in the mediation, or the concerns that there's a conflict and the guardian needs to know about it for some reason?

>> Well, we didn't know. So we didn't know one way or another if the guardian needed to be involved at all. Because we didn't know the details of that guardianship. We weren't asking the question.

Anna, your point earlier about equity and how incoming candidates for these kinds of opportunities are treated the same across the board, and asking that question on every instance, similar to how we would ask for questions related to accommodations and accessibility, makes a lot of sense to us, and I think we could address that issue right from the start.

I think the next question is, what are we -- what should we expect in terms of understanding the details of that guardianship arrangement, right? So understanding what those details are as it pertains to their role with our organization. And then finally, if there's some ambiguity, if there's some gray area, which I feel like we were in when this situation arose, when is it necessary and appropriate to bring a guardian into the conversation?

Because it's not necessarily a legal matter.

>> CATHY COSTANZO: So I guess I would think if you go back to Anna's construct of, what's a normative thing that would be done for anyone, if you think about -- and I was thinking about the situation of, like, your first job, or your first involvement in something outside of your family, with your parents not there every day with you, not school, but just thinking about my first job.

If I messed up at my first job, if there was a problem at my first job, I did something wrong or I -- my behavior wasn't appropriate or whatever. At least in the first several instances I think that there would be no reason to involve -- there would probably never be a reason to involve my family other than if I stole a lot of money, or there was going to be some kind of criminal prosecution of me.

On the other hand, if I was at my job and someone sexually exploited me, or did something that placed me in some kind of danger in the workplace, then I think that the responsibility of the employer to notify my family as my adult guardians, yeah, I think maybe there would be some responsibility -- you know, if there's been some kind of sexual abuse at work or whatever it was.

Then I think, yeah. So I think it really depends on where on the spectrum the thing is, you know? And I know that's probably not the kind of hard and fast line that you would like to get from me, but I don't know how to answer it any other way.

>> Yeah. It is a little squishy, I guess.

>> CATHY COSTANZO: Can you say more about the situation?

>> Yeah. What I can say is a couple of things. One is, our mindset, understanding of the issue, was to treat the situation and the individual as in any other adult volunteer member of our consumer advisory council. And that's what we did.

What happened was when the guardian, which in this case is also a parent, learned that there was some communication between our organization and the individual, let's just say it exploded. There was definitely -- there was definitely a unfortunate circumstance where it escalated unnecessarily, and there was an unspoken, unwritten expectation that the guardian would have been involved at the outset.

It wasn't a legal matter. It was more interpersonal conflict resolution matter, and it put us in a really tight spot, because I couldn't point to, well, here's the university's policy or here's the institute's policy around this, and here how it's backed by either state or federal code or law or statutes.

It was really kind of a values driven process. We're going to treat this individual as an adult, as a member of our consumer advisory, as a value member of our advisory council, and work with the individual to reach resolution.

>> ANNA KRIEGER: I actually think --

>> CATHY COSTANZO: I was going to tell you something funny. I think a lot of this is, again, you know, very specific to the guardian at times, as I said earlier on. And so, there was a parent in Western Mass many years ago who brought the suit to challenge the conditions at the town state school, but really to improve them there.

And he was a guardian for a number of the class members and a friend of ours was running a community program that was serving one of his wards. He called her up to say that he understood that this person was having sex with his girlfriend, and he wanted her to know that he didn't have permission to have sex.

So her job as the residential provider was to ensure that his ward would be celibate. And so she said very politely back, you know, you may think you have that authority. I don't know that any Court has extended your legal authority to that point. But, you know, if, in fact, you have it, you decide how you're going to make that happen. It's not going to be through me or my staff. That's not our job.

And if your ward is wanting to have sex with his girlfriend, that is between the two of them, as long as they're both safe, you know, I'm not playing a role in this.

So I think there are those limit-setting things that have to happen both in terms of being clear about the boundaries and appropriate ways of being involved.

So I think if the family members knows that they're on this advisory council, I think personally that all bets are off in terms of -- I don't think you should have to communicate in a day-to-day, minute-to-minute way about what's happening internal to that committee. Like, too bad.

And I guess if they wanted to revoke the permission to do it, and that's within their authority, that's something you can talk to them about.

But I would not kind of cede a lot of other power to them in the day-to-day operation of how you're going to be interacting with the individual. I don't think you owe it to them. I don't think they can demand that. Like the employer, same thing. You wouldn't have the mother of someone who's your guardian coming into the lunchroom to watch how the social interactions are going at lunch.

Or to tell you the best way to teach somebody to do a particular job. I mean, they may have insights you want to listen to at a different time, but they shouldn't be in workplace supervising their son or daughter or ward.

>> That's helpful. I'm not sure if it would revolve the specific issue that we found ourselves in, but it's helpful for that additional kind of voice on that matter. And I'm going to speak for others perhaps as well. Having been part of this network and this work for 15 years now, where I find that a lot of these issues come into play is the tension between kind of like the more quantitative, whether it's research or law.

And the values-driven approach that advocates talk to do what they think is right. And sometimes those create tension between the two. I think

that's what's happening here. There's a values-driven approach by the guardian that, hey, you should be doing X. Whereas the details of the guardianship doesn't preclude them or us from having discussions trying to resolve these kinds of issues.

And it can be difficult at times to kind of work through this in a productive and amicable way.

>> ANNA KRIEGER: There was something you said, Matt, that was -- we can just reframe, I think. You said, there was nothing I could point to in the law that said, oh, we have the authority to do things this way.

To just make it explicit, Cathy's story illustrated this perfectly. It's totally the guardian's burden to show you what in the guardianship order gives them the authority to have whatever involvement they're imagining.

And it sounds like in this scenario you're describing, like Cathy described in their scenario, there's not going to be anything in the guardianship paperwork that gives them that kind of authority for that level of involvement for the reasons that you just said.

I think one of the natural challenges that comes with guardianships is that there are guardians who just have a false understanding of how much authority they have. And I don't want to stereotype, but in my anecdotal experience, it tends to correlate more strongly with parent guardians, because they've been in this important role in their life fighting for their rights, fighting to protect them.

And there are times when a legal guardianship is established, there's maybe a misunderstanding of what that actually means. And so that blending of the legal authority they have, kind of bleeding into the parental role can be complex. And I really don't mean to totally stereotype, but I think, you know, that's just an anecdotal experience.

And so I think that creates -- that is where I think most likely you're going to have those kind of scenarios come up, whereas that kind of misunderstanding. I think the way another scenario could play out is a guardian thinking they have a right to burst into a workplace, which is in a way what you're describing.

It's slightly different, but you get the analogy. And I think there are -- there is some -- this is where it's so state law dependent, but depending on the state, there might be some good legal authority making it really clear the limits of what that guardian's role is. I think there are enough cases -- often it's about the interpretation of what's in the law, which comes out in a case.

So I think there are more -- issues tend to come before a court for a decision when maybe a guardian is pushing for something they don't really have the legal right to, and then you get a court decision that says, no, this is really outside of the bounds.

So that's why it's really essential, you know, when you're encountering these issues, to find someone in your state who has like a values base who is in your state's guardianship law who shares your values, who can give really on point legal advice about those tensions you're describing.

>> Yeah, that's helpful. Thanks. I don't mean to monopolize our limited time together.

>> CATHY COSTANZO: And I do want to say, it occurred to me in thinking about the educational context, you know, even where you have

parents who are their kids' guardians, you know, through that legal age of majority, parents don't -- when our kids are back in school in real classrooms versus virtual classrooms, it's not like families can just burst into the classroom. Parents can just burst into the classroom to tell teachers how to teach.

Or to say how they want things to happen for their son or daughter. I mean there are those pushy parents who try to do that. But that's not what's customary and that's not what's appropriate. And so I think in the same way, you know, it's true, and you can just kind of build out from there in terms of our interactions in thinking about, you know, other kinds of opportunities for people to participate and the way in which there are boundaries that have to be observed even by guardians.

>> That's helpful. Hopefully this is beneficial for everybody on the call.

If you could just clarify, Anna and Cathy, what is the entity, in this case the -- either the employer or the organization that they're volunteering for, entitled to when that relationship is established?

>> ANNA KRIEGER: I don't think you are, really. Right? I mean, it would depend on -- maybe there's something in a state law that would -- that you could frame that way. Cathy, does anything come to mind?

>> CATHY COSTANZO: I think that -- you're asking what does the guardian have to tell you about the nature of the guardianship? Is that what you're asking? Or the authorities?

>> Correct, yes.

>> CATHY COSTANZO: I'm not sure they have to tell you anything. And that's what gets -- I mean, there's going to be a court order, but do you have access to that court order? Unclear.

So I think you have to really in some ways -- you know, if there was some kind of legal issue, you'd obviously be able to get a copy of it in, like, the context of -- you know, if there was some kind of legal challenge to an action you had taken by a guardian, and then you were trying to understand what is the scope of their authority as it pertains to the person.

I mean, I think you can ask those questions of someone. I think you can ask it of the individual who is under guardianship. I think you can ask it of the guardian. Like, what is the scope of your authority here. We want to make sure we're understanding it.

But this is one of those times where I think guardianship is one of the things that is so widely misunderstood, I think even by guardians.

And so, you know, it's like -- I used to do a lot of training for families, and try to tell a mom of someone who is 19 who has been her -- and has a child with a disability who's been caring for them since birth. You know, a lot of people believe that they continue to be their guardian after the adult child reaches the age of maturity. Because they just kind of feel like that's their job, to be the mom looking out for them. And that the guardianship continues because of the child's disability.

I think there are a lot of people who believe that they're their family member's guardian whether they are or not. Then I think there are families once they become guardians think it means they decide everything about everything. And it doesn't necessarily mean that.

So one of the things we were going to try to talk through, and Anna, you can do it, or I can just keep going, whatever you want.

But there's different kinds of guardianship. So there's a plenary guardianship, which is basically over everything. It's not limited in any way. Those guardianships are, at least in many jurisdictions, now frowned upon. There's the sense that the guardianship needs to be more limited or more titrated to what it is the person needs help with.

So it's not just full blown, you know? It's not just -- and that kind of gets into, well, does the person have -- the guardian have control just over the person's finances? A limited guardianship in some way. A lot of states have things called conservatorships, or it's like a financial -- a guardian over the estate, essentially. And that happens sometimes, as I said earlier, when there's a lot of money involved or the person's inherited something, or -- I was just talking to someone recently, where their southbound received a huge amount of money because some of -- a settlement around birth defects and medications that their mother had been given while they were pregnant.

So their sibling ended up dying, but while they were still alive, they had a couple million dollars the family had in a trust for them. And so therefore, the idea that their southbound could -- and this is somebody who is -- who works in the field, works for a DD council, and was telling me it was one of those heartbreaking things because I wanted to believe that my brother could -- didn't need a guardian, but he needed a guardian for that purpose.

So that's a place where, yeah, maybe you need a guardianship, because at that point in his brother's life, he was incapable of, you know, investing it -- probably I would be too -- millions of dollars and figuring out how to manage all of that.

But at the same time, could make a whole range of other decisions in his own life. And could speak for himself and know what he wanted and know how to express that.

And then there's more limited guardianships of the person, you know, where it's -- it may be your inability -- you know, the court will say you can't enter into contracts, but you can do other things.

>> KATIE JOHNSON: Cathy, if I can just jump in. I'm wondering in bridging Matt's question with what you're saying, it sounds like Matt might not have access to that information, because he's not entitled to know what kind of guardianship it is.

So would your recommendation be from a values-based place that UCEDDs assume the most limited amount of authority that the guardian has? Like, we just assume that they don't have any powers, and I'm going to treat them like an adult who's sitting on my advisory council, and it's going to be really be the job of the guardian to prove otherwise?

>> CATHY COSTANZO: I think that's a bit bolder than I would go, honestly.

>> KATIE JOHNSON: Then could you expand on what -- in terms of -- from my understanding, it seems like you wouldn't have knowledge about what kind of guardianship they're under. You might not be entitled to know the specifics.

So what would you recommend a UCEDD do when -- what assumptions should they or should they not make?

>> Well, let me just quickly add something, because I think that question is really good.

What I was hearing, and tell me if this is wrong, Cathy, that even though we may not be entitled to that information, we can ask about the details of the guardianship that may pertain to this relationship. This engagement as a board member or what have you. And their willingness to provide those details is incumbent upon them.

>> CATHY COSTANZO: Yeah. I guess what I would suggest doing is this. If you know someone who is under guardianship and the guardian is kind of hovering around or present or visible in the person's life in a way, I guess I would just sort of say, you know, we are -- we want to make sure -- it's our expectation that, you know, your ward, son, daughter, whoever, that the person with the disability is going to be an advisory council member.

We want to be able to treat them like every other advisory council member. We understand you're their guardian. We need to know if there's anything about the nature of your guardianship that we need to know in our -- you know, in our interactions with them. Or about your authorities as their guardian in terms of what you expect from us.

And then I think you have to -- if they say, well, I want to approve each and every thing, whatever it is, or I want to sit here in every meeting with them, then you have to really, I think then have the next conversation about, well, do you say more about the scope of the guardianship, why you would feel that would be necessary, blah blah blah blah.

So I guess being in a conversation about it in a proactive way is certainly better. I mean, I wouldn't go looking for trouble, if it's a guardian who's basically said, yes, it's fine for my son or daughter to participate, so on this ACL grant that we have, I've got to tell you, the last thing we want to do is run around having all these separate conversations with guardians every time there's a meeting to talk about how their ward did in the meeting.

But I do think if -- and it could be that some guardians are just so difficult, that you can maybe deal with one person like that, but you could certainly not deal with a whole advisory council full of guardians like that, or as a secondary member hovering in the background.

I mean, I think the thing that's really difficult and complicated about this, and the thing that really sucks, to be quite candid, it's always the person with the disability who gets screwed ultimately if you just get so fed up that you don't want to deal with that guardian anymore.

So it's like how to keep coming back to the person and how to balance what they need and deserve with what the guardian can legitimately ask for.

>> ANNA KRIEGER: And one possible solution to your situation, Matt, where, without knowing all the details, maybe this wouldn't work, but I'll throw it out there. From what you've said, it's hard for -- I don't know New Hampshire guardianship law. But, from my knowledge of guardianship law, it's hard for me to imagine a scenario where there's a guardianship order that covers the kind of involvement this guardian is claiming that they have the right to have.

Again, I don't know New Hampshire guardianship law, but a workaround could be that you reach out to someone, whether it's through the PNA, or through the ARD.

Try to find an expert in New Hampshire guardianship law who can advise you. Even the most restrictive guardianship possible can never cover what this person is saying that they have the authority to do. Then you don't

even need to see the guardianship paperwork, it doesn't matter. And it just might bypass that particular challenge for you. It's probably something they could answer pretty quickly.

Someone would be able to tell you pretty easily for your state law what that outer limit is.

>> CATHY COSTANZO: And I think if there's a plenary guardianship where it's a full blown guardianship, guardians off think that gives them the right to decide each and every thing. And unfortunately, it's probably closer to the truth than we would like it to be.

So that's where it gets really -- you know, I --

>> ANNA KRIEGER: Well, I think it just depends how you frame it. Because I think there is like a -- you know, one way that I sort of look at guardianship, I think guardians think they have a lot more legal authority than they actually do at times.

So, yes, they have -- in some sense, they have a lot of legal authority in the sense that this will potentially decide where someone lives. Whether they have life-saving surgery or not. But I think there's this bleeding -- there's this sense. I can also decide these other types of things. So I think it is more circumscribed -- the authority of a guardianship is more circumscribed than guardians believe.

And you can see how being in that role naturally would kind of -- you could sort of lose perspective.

>> CATHY COSTANZO: And I think if you have kind of a person whose nature is to be a little meddling and a little bit of a busy body, who thinks they know best, it's not surprising that they're going to insinuate themselves into some of these conversations in a way that's inappropriate.

You know, I'm also mindful, though, Anna, like in Massachusetts right now, there's a group of professional guardians who are trying to convince the court that they should eliminate the requirement that there are hearings on whether to have do not resuscitate orders, and can seek decisions around DNRs on the way into a hospital admission, especially during the crisis standards. If the crisis standards of care are invoked, you all know what those are.

If there's a need for rationing because of COVID-19. And so, you know, there's kind of -- on one level, it's very scary. A lot of us have been working for years to limit the role of guardianship, or to at least come up with alternatives to it.

But it is definitely true that there is this segment of the professional guardianship world who is very much alive and active and kind of leaning in absolutely the wrong direction. I don't know how much that comes into play in employment issues, which is what we're here to talk about, but I'm sitting here in with a sick feeling in my stomach about what else we have to deal with today.

>> KATIE JOHNSON: Yeah, I feel like this is such a fascinating conversation. It's sometimes maddening, I think, when you think about some of the ways that these issues are coming up in our world right now.

So I'm glad you touched on it. This has been really helpful. I hope, Matt, for your situation that it's helpful. I feel like I learned a lot. I hope others on the call were able to get some resources or thoughts.

There's a handout that Cathy and Anna made for us, so I'm going to be

disseminating that alongside a copy of the recording, and eventually a tip sheet will be created with some more resources attached to it.

It's past our time, though, so I really, really just want to thank the two of you for coming and sharing your expertise and for everyone for joining on the call. I'm putting in the chat the link to an evaluation survey, but I'll send it over email to all the registered --

>> CATHY COSTANZO: And if it would be helpful, Matt or others, to follow up on any sort of questions or specific situations you have, we'd be happy to talk with you offline.

>> Thanks, Cathy, I appreciate it. This has been fantastic. I do have another meeting that I need to run to.

>> CATHY COSTANZO: It's okay. I'm sure we all do.

>> KATIE JOHNSON: Take care, everybody.

>> CATHY COSTANZO: Thank you for your time.