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Equitable Guardianship Reform: Recommendations for Advancing Equity in the Guardianship System

Webinar Transcript

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Presenter:

Jim Berchtold

Senior Staff Attorney,
Justice in Aging

Sarah Galvan:

Hello everyone and welcome to today's webinar presentation on Equitable Guardianship Reform: Recommendations for Advancing Equity in the Guardianship System. I'm Sarah Galvan, Managing Director of Elder Rights at Justice in Aging. Today I am happy to be joined by my colleague, Jim Berchtold, who is a senior staff attorney also on our Elder Rights team. Before I more fully introduce Jim, I do have a few logistics to cover. Next slide.

Welcome again to all of our participants. You are all on mute, so we welcome your participation in today's presentation through the Q&A function in the Zoom control panel. Also available in the Zoom control panel is the CC button, which enables closed captioning for this presentation. I will be watching the participant questions as they come in through the webinar, and we'll try to address some of the high-level themes during the Q&A segment at the end of the training. Any questions that remain unanswered, however, will be addressed via email following the presentation. You can also use the Q&A function to request any technical assistance that you might need with Zoom, and we'll do our best to try to assist you.

This webinar is being recorded. At the conclusion of this webinar, the slides and recording of today's presentation will be available on our website and will also be emailed to all registrants. We'd also appreciate your participation in our post webinar survey, which will pop up on your screen following the close of the webinar. Next slide.

Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable healthcare, economic security, elder rights, and the courts for older adults with limited resources. Jim is our expert on issues surrounding guardianship reform and improvement, including the intersection of guardianship and equity. Jim's especially passionate about

advocating for policies that promote the appointment of skilled legal counsel to zealously defend the rights and wishes of older adults who are facing or under guardianship.

Just want to mention that before joining Justice in Aging, Jim was heavily involved in reform in the state of Nevada where he had the opportunity to design and build a program in the state that provides legal aid attorneys to all adults facing or under guardianship, which fundamentally changed how guardianship cases were adjudicated in the state. Next slide.

Today's webinar is focused on the intersection of guardianship and equity. Justice in Aging is committed to advancing equity for low-income older adults in economic security, healthcare, housing, and elder justice initiatives. We really strive to address the enduring harms and inequities caused by systemic racism and other forms of discrimination that uniquely impact low-income older adults in marginalized communities. Next slide.

Finally, if you enjoyed today's presentation and want to learn more about our upcoming resources and trainings, you can sign up to join our network. The information is there on your screen. You can go to Justice and to justiceinaging.org or send an email to info@justiceinaging.org.

Now I am happy to turn this over to Jim. Thank you for joining us and sharing your expertise.

Jim Berchtold:

Thanks, Sarah. Welcome, everyone. Thank you for joining us today to talk about guardianship and equity, equitable guardianship reform. I'm happy that you joined us for the conversation. I think it's going to be really fun.

I often like to start these discussions by asking what I like to call the big why. Why are we talking about this? Why is this important? Why should you devote the next hour of your time to thinking about these issues? On that point, I'm going to make something of a little confession. When I started thinking about the intersection of guardianship and equity, my first reaction was, "Does it even make sense to think about equity and guardianship?" In my job I try to keep an eye on what's happening in guardianship all around the country, and rarely does a week go by when there's not some guardianship scandal popping up somewhere. So I thought, "With all that needs to be fixed, with all of the big things that need to be addressed in guardianship, is equity on that list? Or, is talking about equity sort of like talking about the arrangement of the deck chairs on the Titanic as the ship goes down?"

I thought about that for a while, and here's the big conclusion I came to. Guardianship is not like the Titanic. That's the big conclusion. That's the big takeaway from this webinar. No, I'm just kidding. Here's how I came to that conclusion. Unlike the Titanic, guardianship is not going anywhere anytime soon, although there are certainly those who would like to get rid of the system

altogether. Until we have something better and until we have massive political will to make a really drastic change, guardianship is the system we have. So given that, shouldn't the goal be to build the best system possible and to make sure that that system is working for everyone?

Now if that is the goal, one of the big advantages we have as guardianship is actually a very dynamic area of law, unlike some other areas of law. As we sit here right now, even as we speak, really committed, smart, good people around the country are working really hard to improve guardianship in their state. Change is happening and change is going to continue to happen. So as that change happens, doesn't it make sense for us to take that opportunity to center equity as we move forward and to build the most person-centered, person-driven, responsive system that we can possibly build? See, not like the Titanic.

That's what we're going to talk about today. We are going to talk about some basics. What is guardianship? What is equity? And then we'll talk about some areas of guardianship reform, guardianship data, alternatives to guardianship, post-adjudication rights, and think about how we can implement and maintain a real equity focus as we grow those reforms.

Let's jump into some basics. What is guardianship? I'm assuming that since you registered for this webinar, you probably have some basic concept of what guardianship is. But just in case, guardianship very broadly is a legal relationship created when the court gives one person the power to make decisions, financial decisions, medical decisions, for another person.

Guardianship is based in state law. That means that the statutes and the related procedures and requirements vary widely from state to state. Even the terminology varies. In some states you have guardianship. In some states you have conservatorship. In some states you have both. So today when we talk about guardianship, we're really talking very broadly about all of that.

In fact, you may even hear me refer to the guardianship system or even the guardianship ecosystem. Here's what I mean by that. When we talk about guardianship, there is sometimes a tendency to focus on the statutes that authorize guardianship. But anybody who has worked in the guardianship area knows that the statutes are really just one part of what I sometimes call the guardianship ecosystem. That's really the network of interconnected entities and systems that work together to enable guardianship to function. That includes the statutes certainly, but it also includes the court and the attorneys and the judge and the GALs and the investigators and the public guardians, the professional guardians, and private guardians, and the doctors and physicians and healthcare providers, the hospitals and the care facilities and the governmental agencies and benefits providers. So all of that system works together to really allow guardianship to function.

I bring this to your attention because when we talk about guardianship and guardianship reform, we are also talking about how the parts of that ecosystem operate and interact with one another. So today I encourage you to think broadly about what guardianship and guardianship reform really encompasses. So that's guardianship.

Let's talk some basics about equity. Now, I am pretty sure that all of you have seen this graphic before. It's been around for a long time and I apologize for dragging it out again, but I think it's actually a very good visual explanation. In this graphic, everyone's goal is to try to see over the fence to watch the baseball game. In the first frame, everyone is given the same thing to allow them to see over the fence, even though that same thing might not be very effective. That's equality. In the second frame, everyone is given something different to allow them to see over the fence, and that's equity.

I want you to look at those boxes and think of those boxes as the guardianship system. In my mind right now, I think the guardianship system is probably more like the equality side. In many ways, the system is what the system is, and individuals who find that themselves within that system are processed through that system the same way.

But let's imagine a system that's more like the equity side, a system that is responsive to the differences, that recognizes that everyone is different and everyone needs different things to really achieve the benefits of that system. Now that's what we're talking about when we talk about equity within guardianship reform, creating a person-centered, person-driven system that sees the individual as unique, and the system itself wraps around that individual to give that individual what they need to benefit, including recognition that marginalized older adults may need different things. That would be amazing, right? So let's dare to dream.

The first area of guardianship reform we're going to talk about is guardianship data. I don't think that I am exaggerating or sensationalizing when I say that the current state of guardianship data is pretty dismal. Right now, we can't say with any certainty even how many people in this country are under guardianship, let alone who those people are. We don't even know the really general stuff about them like their age, let alone kind of the more granular stuff about them like their race, their ethnicity, their gender identity, their sexual orientation, the language that's spoken, etc. And we certainly don't know why they're under guardianship. What were the facts and circumstances that led to them being under guardianship in the first place? From a data point of view, we really have no idea.

There are many reasons for this kind of lack of data. Across the country, there are multiple court systems, some collecting the data, some not collecting the data. There are multiple computer systems, multiple case management systems that probably don't talk to each other. There are differing statutory

requirements and court rules for what a court must collect and how that data can be used once it's collected.

One of the reasons for the lack of data though is not the lack of asking for it. For decades, advocates have been asking for more and better data to examine the guardianship system. Why is this lack of data and the data itself really critical? Without data, we really have no clear picture about what the system looks like that we're trying to improve. We can't tell where the gaps are in the system, where the disparities might be, where there might be disproportional impacts. And we also can't tell where to focus reform efforts, let alone whether those reform efforts are actually working once we put them in place.

That lack of data really makes guardianship reform sort of this best case exercise where we do the best we can. That becomes especially problematic when you're talking about marginalized communities, because every indicator points to an increased risk that marginalized older adults are likely to come into contact with the guardianship system.

Here's what we know, and we don't know this because of data. We know this because of anecdotal evidence from news reports, and from reported cases, and from the experience of people actually in the guardianship system. But we know that there are some set of factors that are risk factors for guardianship. Those risk factors, not surprising to anybody who operates in the guardianship world, is some combination of advanced age, sex, women more likely than men, poverty, cognitive decline, physical decline, chronic health conditions, living alone and/or living in isolation, and living in a nursing home or some other institutional facility. What we also know, and by we, I mean researchers who are way smarter than I am, we also know that with respect to each of those factors, marginalized older adults are at increased risk due to a lifetime of systemic racism, discrimination, and disparity, all of which combines to negatively impact the aging process.

We know that as a percentage of older adults, racial and ethnic minorities are increasing. They are increasingly likely to live in poverty and increasingly likely to live with dementia, disability, other chronic health conditions. And, they're living in institutional settings at higher rates than ever before. Now despite all this, we really don't have the data to have a nuanced data-driven conversation about what that means. What is guardianship's impact on marginalized communities, and what are the potential disparities that marginalized older adults may face within that system?

Here are some recommendations to try to fix that. Congress needs to establish and fund a guardianship court improvement program that grants money to state courts and requires those courts to collect data and to provide that data. And when I say data, data specifically including data on marginalized communities, and then provide that data to a federally funded national repository that can be accessed by advocates, research, and policy makers. This

is not a new idea. This has been around for a very long time, and we also have a really good example of it working in the child welfare court improvement program. So we know that it can work.

But in conjunction with that, courts need to expand the data that's actually being collected to ensure that they're capturing data on marginalized older adults. That would include things like race, ethnicity, sex, gender identity, sexual orientation and expression, transgender identity, language spoken, tribal affiliation, and the type of disability that actually led to the guardianship in the first place.

To do this, high courts will have to create and implement new rules about what the lower courts are required to collect and how they're required to collect that. The easiest way to do that is probably to create and utilize standardized court forms that actually ask for that information in the first place.

I am assuming that not everyone on this call is either a member of congress or a highest state court justice. So what can you do? Regardless of where you fit into the guardianship system, think about your organization and think about the data that is available to you that you can collect, and what your organization can then do with that data.

At my old legal aid organization, my former legal aid organization, when we started representing adults under guardianship, we also started collecting data to show what that representation looked like so that we could then take that data and present it to policymakers to argue for the change we wanted to see. And I will tell you, when you are the only person in the room with any data, that data can be very persuasive. So think about the change you want to see, and then think about the data that might be available to you in your organization that you can start collecting to argue for that change.

The next area of reform that we're going to talk about is guardianship alternatives. What do we mean by alternatives? Really it's any support or arrangement that isn't guardianship, that meets the person's needs, but allows them to retain more autonomy and self-direction than they would have under guardianship. This could be anything from as easy as utilizing a joint bank account to something as complicated as creating a trust and appointing a trustee. Now in theory, utilization of these alternatives would allow you to either narrow the scope of the guardianship or to avoid the guardianship altogether.

Comparatively, less restrictive alternatives as a reform effort has been pretty successful. Numerous state courts now require in their statutes some consideration of less restrictive alternatives, and the Uniform Guardianship Act actually prohibits the granting of a guardianship if there is a less restrictive alternative available to meet the person's needs. Unfortunately, not everyone has benefited equally from these reforms, because the promotion and

implementation of less restrictive alternatives in marginalized communities has lagged behind those advancements.

Let's take, for example, powers of attorney. A power of attorney is a super easy document that you sign. In that document you designate a surrogate decision maker who can make decisions for you, healthcare decisions, medical decisions, financial decisions in the event that you are unable to make those types of decisions for yourself. However, to execute that document, you need the requisite legal capacity, which means that document typically has to be signed well in advance of the push for guardianship. That means advanced planning. Now, people generally are really bad at advanced planning, but the rates of advanced planning in marginalized communities are even worse. According to one study, 82% of Hispanic adults and 77% of black adults had done no advanced financial planning, and black adults were four times more likely to have no advanced healthcare planning as compared to their white counterparts.

But, there are promising initiatives to try to increase the rates and utilization of advanced planning in marginalized communities. Some initiatives have partnered with faith leaders to educate black communities about advanced planning. Other initiatives have trained peer facilitators in black communities, community members who are trained and then are able to assist other community members to complete their advanced planning. Some initiatives have partnered with local community icons in the black community to increase utilization and outreach of legal services clinics.

What I really want to highlight about all these initiatives is how they went about doing that. Each of them utilized a culturally competent, community-centered, community-grounded focus and approach, and they intentionally went about building trust with the community by partnering with existing community institutions and trust points in that community.

So then the question is, how do we take those great lessons learned from these innovative projects and apply them to guardianship reform to increase the rates of utilization in marginalized communities? Here are some recommendations for that.

Congress and state governments need to fund projects that are testing these innovative program models that are to increase the use of advanced planning and alternatives in marginalized communities. Those programs need to utilize these creative strategies, community-based strategies. Successful programs should be scaled up and their best practices should be shared widely so that they can be replicated. Those programs also need to develop materials, outreach and educational materials specifically targeted to those marginalized communities. So that of course means materials in different language, but it also means materials that are developed with a cultural awareness and cultural sensitivity to that community. So not all the educational materials will be exactly the same. Finally, state government needs to study the barriers to the utilization

of alternatives to guardianship in marginalized communities and then implement solutions to those barriers.

And by this I'm not just talking about advanced planning; I'm talking about any alternative to guardianship. That could be anything from Meals on Wheels to in-home care services, even to something like access to banking services.

Now, I'm assuming that not all of you on this call have your finger on the funding mechanism of state government. So what can you do? In whatever role you have within the guardianship ecosystem, and even if that work doesn't have anything to do with alternatives, I encourage you to take stock of your organization's interaction with marginalized communities, and then evaluate whether there's anything that you can do in your organization to incorporate some of these really promising practices and these innovative strategies. Learn from these programs. Are there ways that you can build trust, that you can partner with the community in order to increase your effectiveness and the reach of your services? I'm almost sure that there are.

The last area of guardianship reform we're going to talk about is post adjudication rights. What do we mean by post adjudication rights? We mean the rights that the person retains once the guardianship is actually in place. For many years, reform efforts really focused on what's been called kind of the front end of the guardianship, meaning the process leading up to the actual granting of the guardianship to make sure that the due process rights of the person facing guardianship were protected. Obviously very important stuff.

More recently, there has also been a focus on the rights retained by the person once they're actually under guardianship. This has been done in a number of different ways. One of the ways that I really, really love is by the creation of statutory bills of rights, which are basically codifications of a list of rights that the person retains once they are under guardianship. A number of states have had these for quite a while, although the rights that were actually protected under these statutory bills of rights really varied very widely from state to state. The sort of push to create these bills of rights really got bumped to the next level in 2021 with the Fourth National Guardianship Summit. At that summit, one of the recommendations was that a model bill of rights be created, which could then be adopted by states statutorily. In response to that recommendation, the National Guardianship Network created a model bill of rights, which in 2022 was adopted by the National Guardianship Association.

I want to be super clear that I really like the model bill of rights. I think it's a good piece of work, and I really, really hope that states adopt it. Although to my knowledge, as far as I know, no state has yet, but I hope they do. But that doesn't mean of course that I don't have a couple of suggestions for improvement. Specifically, I think the model bill of rights may fall a little short when it comes to the protection of cultural identity and cultural participation of marginalized older adults. To be clear, the model bill of rights does say that a

person under guardianship has the right to a competent guardian to advocate for your cultural practices. But, that is not the same as retaining a fundamental right that you can enforce to maintain your cultural identity and maintain your cultural participation. And those rights have been considered fundamental for a very long time.

In fact, Eleanor Roosevelt chaired the UN committee that incorporated those rights into the Universal Declaration of Human Rights in 1948 after the Second World War. They have been included in numerous human rights documents since that time, including the International Covenant on Economic, Social, and Cultural Rights, under which the UN actually issued some really, really helpful and persuasive guidance and encouraged these rights to be viewed broadly to include things like ways of life, language, nonverbal communication, rights and ceremonies, food, clothing, customs and traditions, and many other things. That guidance also noted the need for special protection of the cultural rights of women, older persons, persons with disabilities, minorities, indigenous persons, and persons living in poverty.

Let me back up. The United States signed this multilateral treaty in 1977, but it has not yet ratified that treaty through Congress. But there are other treaties that similarly incorporate this concept of cultural identity and cultural participation as fundamental rights that have been ratified through Congress. So not only is there a potentially legal basis and certainly a moral basis for including these cultural protections, but there's also just a really practical one.

Research has shown that a strong cultural identity and participation actually protects the mental health and wellbeing of the individual. It increases the sense of belonging and purpose and social support and self-worth. It increases resilience, it enhances self-esteem, engenders pro-social coping styles, and it protects against mental health. It even buffers the psychological stress associated with discrimination.

Given all that, why wouldn't we include these as fundamental rights and protect them for marginalized older adults who find themselves under guardianship?

Here are some recommendations to do that. Cultural identity and cultural participation should be included as fundamental rights in state bills of rights. And in the model bill of rights. States that have not enacted bills of rights should enact them with the addition of cultural participation. States that already have model bills of rights should amend them to add in cultural participation and identity. The Uniform Guardianship Act should be revised to incorporate the model bill of rights with the inclusion of cultural participation and cultural identity. And in states where there is no model bill of rights, or where there is a model bill of rights that doesn't include these fundamental rights to cultural participation and identity, those rights should be added in to the order granting guardianship to protect the marginalized older adult. Guardians, and really anybody in that larger guardianship ecosystem, should be trained on how to

maintain someone's culture, as well as cultural competency and cultural humility.

So, what can you do? You can advocate in your organization for that very same thing. You can advocate that the people within your organization get training on cultural competency and cultural humility, and you can review your organization's materials and your organization's interactions with marginalized older adults to make sure they are really done in a culturally sensitive, culturally appropriate way.

Those are all the areas of guardianship reform that we're going to cover, but I do have a couple of comments just to close up. As Sarah mentioned earlier, what we've talked about today is based on a series of issue briefs that we released last year called Equitable Guardianship Reform. By necessity, this has been a very brief overview of what's covered in those briefs. So if you are interested in more detail, I really encourage you to read them. They are available on the Justice in Aging website.

Secondly, what we talked about today is by no means intended to be exhaustive. I do not claim to know everything there is to know about equity in guardianship, but my suspicion is in fact that this is really just the tip of an iceberg. And once we get under the water and start exploring a little bit, I think we'll see a lot more. I think we will have more questions to ask and answer and more topics to discuss. I see that as a really good thing, because really one of the big goals of this presentation today, this discussion today, has been to talk about something that previously has not been a focus of the reform conversation. I see questions and topics and discussion as really, really positive things.

So for the last time, what can you do? Well, you can obviously continue this conversation. You can talk to the people in your organization and bring equity in guardianship into the course of your organization's dealings with marginalized communities. Hopefully some of the recommendations that we've talked about have resonated with you in some way.

But in addition to those, in addition to everything that we've talked about, I would also actually really encourage you to talk to your legislators about how equity might be incorporated into guardianship in your state. This may take a little research on your part. I would encourage you to find the person in your state who is a champion for guardianship reform. That may be a legislator, it may be somebody who works in government, it may be a judge, or it may be somebody who works at a legal aid organization or a nonprofit. But reach out to them and let them know you're interested. Let them know you support the work that they're doing, and tell them about your experiences and your ideas for improving the guardianship system.

To that end, we would like to keep this conversation going as well. Justice in Aging is holding an interactive Guardianship Equity Roundtable on January 30th because we want to hear from you. We want to hear about your experiences and your ideas to see how they can inform our work on this topic as we go forward. I will say, just be warned, this is not a typical webinar presentation. It is really structured as a small group participatory conversation. It's kind of cameras on, interactive, let's talk about it. To facilitate that conversation, space will be limited, but anyone who has attended this webinar today will receive an invitation to that roundtable. So if you are interested in sitting down and talking about these issues that we've talked about today, I would really watch your email and I would love to talk to you more about them at the roundtable.

If you are unable to make it to the roundtable, I still want to hear from you. If you have ideas, if you have thoughts about equity and guardianship, I would love you to send me an email. My email is jberchtold@justiceinaging.org and I would be thrilled to hear from you. That's all I have, but I think Sarah maybe has some questions.

Sarah Galvan: Thank you, Jim, for all of the great information. We do have a few questions. I'll start probably in the same order that you were covering topics. You mentioned that we do have a lack of data on guardianship and the people who are impacted by the system, but we do have a question specifically about whether you know of any guardianship data or maybe like a state or locality that's looking at LGBTQ+ older adults.

Jim Berchtold: There are states around the country. As I say, guardianship data is very sporadic and dispersed. It really depends on the court system that's collecting the data, which is problematic because the courts don't share. And even if they shared, there's no place to share it to. There's no big federal umbrella collecting this information. So for a researcher, if you needed or if you wanted to research a particular issue, you would literally have to go to every court in the country to figure out what they were doing. But there are some courts that are doing really, really innovative good things. Off the top of my mind, I know that Portland is doing some really good data collection.

I also want to mention that there are projects ongoing to try to standardize the data that's being collected so the courts are kind of looking at those data elements in the same way. One of the great projects is the project by the national state courts, which is the National Open Court Data System, maybe. I don't know. But it's a great project. And so what they're doing is they're kind of standardizing the data elements, and then providing the tools and training to court to try to encourage them to collect that information. So yes, there are initiatives right now and courts right now that are trying to collect that information. But honestly, they're sort of few and far between.

Sarah Galvan: Thank you. Jim. You also mentioned the importance of advanced planning and access to advanced planning as one of the recommendations in this

presentation. Do you see that supported decision-making specifically is kind of lumped in with some of the initiatives that you would recommend?

Jim Berchtold:

For those of you who don't know what supported decision-making is, supported decision-making is really an arrangement where someone designates supporters to assist them with making certain decisions while maintaining the ultimate control to make that decision themselves. So basically they surround themselves with advisors who will provide information to allow them to make a good decision. This could be in an informal setting, or it could be a more formalized arrangement, sometimes even through a supported decision-making written agreement.

Supported decision-making as an alternative to guardianship is great and it's catching on and it's getting a lot of traction, but the data seems to be showing that it may be better for some people than others depending on the needs and the abilities of the person. Let's compare it, for example, to a power of attorney. It really depends on the situation what is more effective. Supported decision-making is great, but in a really extreme example, let's say for example, someone gets into a car crash and is in a coma. That supported decision-making agreement is not going to avoid a guardianship because no one has the right to make decisions under that supported decision-making agreement except for the person now currently in a coma. So in that case, a power of attorney might be more effective.

So I think all supports really work together. I think that's the best way they work, is by really creating a web of support to give the person what they need to retain their autonomy and their decision-making authority. And that could be anything from supported decision-making to powers of agreement. You could do those in conjunction. But it also means everything from, it could mean joint bank accounts, it could mean home services, it could mean Meals on Wheels, it could mean bank accounts that can be accessed by loved ones. It could be a range of things. So I think supported decision-making is great. I think all the alternatives are great. It's like having tools in your toolbox. You have to use the tool in the right situation for the right thing.

Sarah Galvan:

Thanks, Jim. We also have a few questions about the bill of rights or the model bill of rights. First, is there a way for people to find out if their state has one already? Or is there a place where you can go and see which states have them?

Jim Berchtold:

I don't have a complete list of all the states that have them, and even if I did, it's really a tricky process to say. Because some states, they think they have a bill of rights, but really all their bill of rights says is, "You retain the rights that you had before you entered this guardianship." So I mean, not great and a little hard to enforce sometimes.

Other states have really good bills of rights. I will just toot Nevada's horn since that's where I live. Nevada has a great bill of rights that I think was based on

either New Hampshire or Vermont, I can't remember, that really just sets out the rights that a person retains, the right to counsel, the right to be involved, the right to financial planning. I mean, a whole list of rights. Florida has a good one. It was actually Florida's bill of rights that served as a basis for the model bill of rights that was prepared, amongst other things. I think Michigan has a good one.

As far as whether your state has one, the only way to really find that out would probably be to do just a little statutory research. But honestly, if you got on Google and you said, let's say you live in New Hampshire, "New Hampshire bill of rights for people under guardianship," you probably would come up with the right statutory site. So it's not that hard to find the bill of rights.

One thing that I will just mention really quickly, bills of rights I love, and the reason I love them is because as an attorney who represented people facing or under guardianship, it gave you something to enforce. Regardless of what the situation was that your client was facing, you could go to that bill of rights and say, "That violates this right."

But importantly, a bill of rights is only good if it has an enforcement mechanism. There's got to be some mechanism by which the attorney can bring it to the court and the court can do something. So having a bill of rights, that's just kind of in theory, "Oh, isn't that great to have a bill of rights?" It doesn't really do anything. So bill of rights with enforcement mechanism that people know about, the people under guardianship actually have to know what their rights are. So there should also be a requirement that they get a copy of that bill of rights. So bills of rights are great. If you want to find out more about them, I encourage you to look at the bill of rights to see if there's a bill of rights in your state.

There's also a really good article that was written in conjunction with the Fourth National Guardianship Summit that I would be happy to send to anybody if they're interested. Just email me and I will shoot you that information.

Sarah Galvan:

Thanks, Jim. That actually answered one of the other questions, which was about enforcement under the bill of rights. Thank you for going ahead and answering that.

We have a few people who have asked about whether data from public guardians could be useful to answer some of these gaps that you mentioned. I'm wondering if you have any thoughts on that or have seen that happening already?

Jim Berchtold:

I haven't seen it happening, but my answer in response to that question is yes, absolutely. I think data from everywhere is beneficial. I think data from legal aid organizations is great. Public guardians would be amazing, yeah. I'm sure they have some great data.

Now, the logical place to get a real full picture of the data though, it's got to be the court. The court is the entity that sees every guardianship case. So the public guardian information, yes, would be incredibly useful, but the public guardian doesn't see every guardianship case. They see some portion of the guardianship cases. So you would have to take that and extrapolate to the guardianship population as a whole, which may not be an accurate representation because the cases that go to the public guardian may not be representative of all the other guardianship cases. So valuable? Yes, absolutely. Comprehensive? Probably not. We really need the courts to get on board. But as I said, whatever your organization is, figure out what data you have available to you and how you can use that data to argue for the change you want, because it really is effective. Data can compel change.

Sarah Galvan: Thanks, Jim. Going back to enforcement in the bill of rights, you mentioned that Nevada has a good model. Can you explain what the enforcement mechanisms look like in that one or what your recommendations would be for that if someone was looking to add that to their state's bill of rights?

Jim Berchtold: I haven't looked at the Nevada bill of rights for a while, but it allows anyone, the person under guardianship or the person's attorney or anyone, to bring this to the court and enforce that right. If I remember correctly, I think there's even a penalty associated for violation of the right, which is kind of critical, right? It's great to be able to fix it, but it's also great to be able to kind of slap somebody's hand for doing it in the first place. So it's some combination of those things. I should have mentioned too that Utah has a really good bill of rights that you can look at. So it would be some combination of all that.

Again, if you're interested in the bill of rights, just email me. I can email you some information. I could email you a copy of the Nevada bill of rights or some other good bills of rights. And I could also email you that article, which I think has an appendix with a listing of the states and the status of the bills of rights in the various states. It's probably not up to date because it's a few years old, but it would be a good place to start looking around.

Sarah Galvan: Thanks, Jim. For advocates and people working in the community now, if they're wanting to reach out to marginalized communities to encourage them to engage in advanced planning, do you know of any good resources that have maybe plain language or sort of accessible materials? I know The Conversation Project seems to be liked by a lot of groups. I'm wondering if anything else comes to mind.

Jim Berchtold: No. Well, let me say, yeah, I think that's a great idea, Sarah. The initiatives that I mentioned earlier in the presentation, I found them because I read studies relating to them. So it was talking about the program and the effectiveness of the program, but it really didn't show the materials that went along with that. So I don't have a good answer to that question, but it would be great for me to find out. So if you want to email me, I will look around and see what I can find.

Sarah Galvan: Thank you. Let's see here. I'm just looking at if we have any questions remaining. Just wondering if you could clarify, someone was asking that if guardianship records from the court are public, why can't the data that we need be gathered from them? I'm wondering if you could just clarify that.

Jim Berchtold: Your question assumes the guardianship records in the court are public; they're not. In some states they are. In some states you can access at least some of the records, although some things are filed under seal or kept confidential, things like medical records and other things considered personal, financial. So you may be able to access some records, but that's only in some states. In some states you can't access anything. And even if you could, even if you could, to do a widespread research project to analyze, let's say, guardianship's impact on marginalized communities. And some courts aren't available online. So literally you would have to go to hundreds of courts around the country and look through case files to pull out that information. So it's really just completely impractical.

And the numbers that we do have, there are numbers thrown around as far as the number of people under guardianship in the country, those are really based on a few courts who make their records public. And then that number, those records are analyzed and extrapolated to the country as a whole. So it's basically a really educated guess. We don't have any idea about the big things, let alone the minutiae things as far as guardianship. And the way the court system is set up and structured from state to state, it makes it right now almost impossible to find.

So that's why, in my opinion, there has got to be some federal action. Now, there have been bills at the federal level to try and increase control over state level collection of this information. In fact, just a couple of years ago, there were two bills that were introduced. None of them have passed. I think even there's a federal bill kind of percolating right now on this issue. So I think that's what it's really going to take. I mean, this has been an issue at the federal level for a really long time. It has been discussed in congressional hearings. The GAO has done several reports about it and told Congress, "There's no data. We need more data." But I think it's going to take federal action, because otherwise you will never get all those court systems to operate on the same page.

Sarah Galvan: Thank you, Jen. We do have some more specific questions, so we may save some of these to answer you separately after this training. But Jim, before we kind of wrap up today's webinar, do you have anything else that you'd like to share with the audience?

Jim Berchtold: No, no. I would just like to once more reiterate if you are interested and if you want to continue the conversation, I would love to hear from you at that roundtable on January 30th. I think it's going to be really interesting opportunity. Unlike this, you won't have to listen to me talk for an hour, which will probably be just a blessing for you. I want to hear from you about your

experiences and your thoughts and what's going on in your state and where are the gaps that you're seeing and the disparities that you are seeing in your systems. I'm really excited about it. I know it can be slightly intimidating to share, but again, it's going to be a small group situation, and it really is just a conversation on this topic to start a good discussion. So please, if you are interested and you are available and you are eager to participate, look for your email and register for that.

Sarah Galvan:

Great. Well, thank you, Jim, again for sharing your expertise today and getting to so many of our questions as well. Thank you again to everyone who joined us today. Thank you to Jim. And as a reminder, some of the questions that went unanswered we'll follow up with via email. You can feel free to reach out to Jim who has kindly put his email address there on the screen.

We hope you will complete our post webinar survey today. Your feedback is really important for ongoing programming. So thank you all, and have a great rest of your day.

Jim Berchtold:

Bye everybody. Thank you.