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National Center on Advancing
Person-Centered Practices and Systems

NCAPPS Webinar Transcript: Choosing a Health Care Power of Attorney: Who's Your Who

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SPEAKERS

Leigh Ann Kingsbury, Alixe Bonardi, Shawna Hall, Alva Gardner, Mary Beth Lepkowsky, Deja Barber

Alixe Bonardi 00:00

I would like to welcome everyone to today's NCAPPS webinar, choosing a healthcare power of attorney who is your who. My name is Alixe Bonardi. Next slide, please. And I am delighted to be welcoming you to today's webinar. I am one of the co-directors of the National Center on Advancing Person-Centered Practices and Systems and I would like to thank you for joining us to learn about advanced care planning and healthcare decision making. A visual description I'd like to offer is I am a white middle-aged woman with shoulder length, brownish hair, and I am sitting in my office with colorful abstract art behind me. This webinar series is sponsored by the National Center on Advancing Person-Centered Practices and Systems, which is funded by the Administration for Community Living and Centers for Medicare and Medicaid Services. Next slide please.

Alixe Bonardi 01:05

The goal of our center is to promote Person Centered change that makes remote systems change that makes person centered principles not just an aspiration, but a reality in the lives of people across the lifespan. Next slide, please.

Alixe Bonardi 01:23

And I'd like to go over a few webinar logistics. All participants are muted during this webinar. And we have the chat feature open which everyone we hope will use to post questions and communicate with folks. Towards the end of this webinar, our speakers will have an opportunity to respond to questions time allowing that will be entered into chat. If time does not allow, we will make sure that the speakers can answer afterwards and get that information back on our website. This webinar is captioned in English and Spanish and there are links that will be dropped into chat to make the captioning available. And this live webinar includes poll and evaluation questions. And please be prepared to interact during polling times. Next slide please.

Alixe Bonardi 02:15

After the webinar, we welcome follow up questions and feedback to our web address, ncapps@hsri.org. And this recorded webinar, along with the PDF version of the slides and plain language summary will also be available within two weeks on our website. [NCAPPS.acl.gov](https://www.ncapps.acl.gov). Next slide please.



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Alixé Bonardi 02:46

To get started, we'd love to hear from you. Our panelists would really like to know who's here, a poll will be opening on your screen and should be available right now. And we would like please enter how you self-identify. Please note that there's also a few other options down at the bottom, you might have to slide that gray bar to scroll down below to the very bottom of the over 402 participants that are over 400 participants that are joining us here today. I'm starting to see responses with a broad range, we will give people another five seconds or so to complete to complete the poll. And, as my colleague Saska noted, please go ahead and type into chat, any other categories you would like to identify yourself as. So now let's take a quick look at who is available here. We have, we have quite a number of folks who are I identify as social workers, counselors, or care managers. We are welcoming. Just about a quarter of our participants identify as self-advocates or advocates welcome, as well as family members and people with disabilities who use long term supports and services. Additionally, we have quite a number of about 28% who identify as government employees as employees of community or faith-based provider organizations, researchers are with us as well. And we also have folks who have joined from HMO or managed care entities. We're delighted that you all are here, and this is this is something that our panelists really are glad to know about as well. Next slide please.

Alixé Bonardi 05:05

And speaking of our panelists, we have we have a number of panelists here today. And I would like to very briefly introduce them. We have two co facilitators. Leigh Ann Kingsbury is the principal consultant and gerontologist at InLeadS Consulting, who has supported people with complex health care and disabilities for more than 30 years, and who authored people planning ahead, a guide to communicating health care and end of life wishes. We also have joining us Mary Beth Lepkowsky who is a training and organizational development consultant and leads Helen Sanderson Associates USA. She is an advanced care planning facilitator and co-developer with Leigh Ann have a facilitator training program called Person Centered approaches to healthcare decision making. We have three panelists joining us as well. Alva Gardner, who is a speaker, trainer, and consultant who works with companies and organizations to increase disability awareness and person centeredness. Within the work they do. She will share her insights as someone who is new to the idea of advanced care planning. Deja Barber is from Raleigh, North Carolina, and is obtaining a double Master's in school and rehabilitation counseling from NC State University. Deja has served on numerous community boards, and she will share her reflections from speaking with her family about advanced care planning. And finally, Shawna Hall is part of the Helen Sanderson Associates team and a spiritual director. She will share her experience of choosing a healthcare power of attorney as a young adult and reflecting on updating her preferences when preparing for a recent surgery. We're delighted you all are here. And with that, I would like to turn this over to Leigh Ann.

Leigh Ann Kingsbury 07:27

Thanks, Alixe. Hi, everyone. Thanks for joining us today. We're really glad you're here. We really want you to hear from our panelists today. So, we have just a few minutes of introductory information sort of level setting so that we're all on the same page. And just kind of operating from the same perspective. Some recent research highlighted some challenges with advanced care planning. And if you look historically, at advanced care planning, what we know is that kind of originally, if you will, the idea



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behind advanced care planning was that we would identify our healthcare wishes we would tell somebody what we want. And then if something happened to us, that person that we had identified as our decision maker, which we're calling a power of attorney would be able to act on our behalf. And we've learned that it doesn't exactly work that way. And I'm going to pause for one second because I realized that I needed to do visual introduction. And I forgot to do that. So, I apologize. I am Leigh Ann Kingsbury, as Alixe said, and I am a white woman with dark brown hair. And wearing brown glasses. I have a black, white, and tan kind of patterns t-shirt. And in my office today behind me is a bookshelf with books on it and a set of closed curtains that are sort of red and gold in color. All right back to advanced care planning. So, the idea originally behind advanced care planning was that we would identify our health care wishes we would tell somebody what we wanted. And then if we were unable to act for ourselves that that person would act on our behalf. And there's some recent research that has challenged that assumption. And we'd like to talk just a little bit about kind of what the data is telling us. And what we know works in advanced care planning. And really what we've learned is a is a pathway to take. So just to get us all on the same page. advanced care planning, we talk about this today. What we're talking about is really that process of holding conversations and giving considerations to the decisions that someone you yourself or someone that that you are supporting or a loved one might want in a healthcare situation, really anytime someone's interacting or engaging with the healthcare system. Sharing those wishes, very significant part of advanced care Learning, you might have very clear wishes about something that you do want or don't want. And holding on to that and knowing that is important. But it's not helpful if you haven't shared that information with someone else. Preferably writing them down, though, writing those wishes down is not a requirement. But it's preferable, it makes it a little more formal. And it really helps the person that you're identifying, to carry out those wishes. And then the third piece of this is identifying someone, someone you trust, who can act on your behalf. If you cannot, someone you believe will honor your wishes, and someone who you think really can act, when tough situations arrive when it may be difficult to make decisions. Next slide, please.

Leigh Ann Kingsbury 10:54

So, as I said, there's some recent research that has presented some challenges with advanced care planning. So, what do we know what does the data tell us? I'm not going to read through each one of those. But I would like to highlight a couple of those. One is that just writing down your wishes, may not ensure in fact that they are honored. And the other tied to that very clearly tied to that is we know that people change their minds. And so, what you think you might want today, or what somebody you're supporting might want today may be very different than what you want a year from now or five years from now, or 10 years from now. And so, reviewing and going through those conversations over time is really, really important. One of the reasons that advanced care planning and of writing down your wishes might not always work is this third line on the slide, predicting the hypothetical, is really difficult. If you are essentially healthy, and you don't have any significant engagement with the healthcare system, other than you're visiting the doctor once a year, trying to predict in some hypothetical fashion, what do I think I would want if it is really hard to do, it's really hard to do. And again, we know that people change their minds.

**Leigh Ann Kingsbury 12:23**

The other thing that really impacts people who live with disability diagnosis is that some other recent research has shown that a majority of physicians in the United States believe that people with disabilities have a lesser or worse quality of life than people without disabilities. And we know if you use COVID, as an example, we know that there were COVID policies around life sustaining treatment, that excluded people with disabilities. And so all of that kind of pushes back against this idea that if you just write it down, and you just tell somebody simply you'll be okay. We need to do a little bit more than that. Next slide, please.

Leigh Ann Kingsbury 13:14

I thought this was a really powerful quote, this is a quote from a physician who happens to be an expert in palliative care and care at end of life. Dr. Randall Curtis, who runs the Palliative Care Center at the University of Washington, who also is a physician who's living with ALS, otherwise known as Lou Gehrig's disease. And, and one of the things that Dr. Curtis says is, "I haven't necessarily made all of these specific decisions yet. I haven't, haven't said yes, I want or no, I don't want. But if we're going to look at the effectiveness of advanced care planning, we have to consider the fact that having those conversations absolutely brings me comfort, absolutely helps me prepare for making these decisions later on." And that's a critical piece of what we know works. Holding conversations over time, is one of the absolute elements of advanced care planning that works. Next slide, please.

Leigh Ann Kingsbury 14:22

So, what does work? It is absolutely all about relationships, relationships with people you trust, it may be about finding new relationships. It's about relationships with your health care provider. What does that person know that you want? What have you shared with them about really what your goals for your care are? And again, holding those conversations with all of those folks, multiple times over time when we asked kind of J And really what is it people expect from their healthcare decision makers? What we know is that people want somebody that can respond typically in a stressful situation. People want someone who has some flexibility. I think I want this, but I want you to listen to what the physicians are saying, I want you to listen to what other clinicians are saying, because there might be other information there that could influence that decision making. And most importantly, that the decisions that a healthcare decision maker or a power of attorney is making are made in the context of respecting the person the individual's core values and goals. And that last piece, again, just another quote that I thought really captured well, this idea is that when we think about clarifying one's goals for healthcare, we think about writing down our wishes, it's really not a legal task at heart, it certainly does include a formal formality and there is legal formality there. But it's much more an exercise in communication. Next slide, please.

Leigh Ann Kingsbury 16:12

So, who can be a power of attorney let's just talk a little bit about that? When we talk, in this case, we're talking about power of attorney, we are specifically talking about a power of attorney for healthcare. And first of all, it has to be someone that the person chooses. And we will make an assumption here that the person trusts that that individual, if someone is going to choose a power of attorney, they must have the capacity to do so. And we don't have time in this webinar today, to spell out all of the continuous contingencies for capacity, but it really is about understanding that you have the authority to



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make a decision and the risks and benefits of that decision. And that those decisions, that decision really aligns with your values. So, someone that the person chooses, and trusts can be a healthcare power of attorney, they have to be an adult, you cannot be a minor child, someone who can make thoughtful decisions, again, in situations that are probably pretty stressful. Someone who will absolutely take the time to get to know the person and understand what matters to the person and someone who, even if they don't fully agree or they're not certain they would make the same decision, someone who will honor the person's wishes as stated. Next slide, please.

Leigh Ann Kingsbury 17:40

So, who cannot be a power of attorney? In most states, if you are an employee of an individual's health care provider, you cannot be a healthcare power of attorney. And, you know, in community-based disability services, we often don't think of ourselves as healthcare in the traditional sense of the word. For this conversation we are if you are working in community-based health care, community-based disability services, you are considered part of an individual's health care system and a health care provider. So, an employee of a person's health care provider cannot be a power of attorney, a minor child cannot be a power of attorney, someone who has a legal guardian or conservator themselves cannot be a power of attorney. And that's because from a legal standpoint, in the eyes of the law, that person is not considered competent. And if they're not considered competent, they won't have capacity to be a healthcare decision maker. And very importantly, someone who is not chosen by the person. Next slide, please.

Leigh Ann Kingsbury 18:51

We know that there are a lot of people with disabilities who may be disconnected from unpaid relationships in their lives, they may not have other people in their lives aside from paid relationships, which are very important, and maybe the reason people are living day to day life in a community setting. But people may be disconnected from unpaid relationships. If someone has not identified a health care decision maker, they haven't identified a power of attorney. There are 44 states in 44 states and the District of Columbia. There are statutes on the book there are laws that say if you don't have a healthcare power of attorney, here's who can make a decision for you. We will see if you have a spouse, if you do not have a spouse, we will look and see if you have an adult child. If you do not have an adult child we will see if you have an adult sibling, we will look to next of kin. In some states, some of the other hierarchy. The other elements in that hierarchy are close personal friend or other options as directed by the state. This is a really generalized list, I just want to point that out. This is sort of what it generally looks like. But you really need to know what your state rules say about that. And the last piece that I'll end with is, you know, unfortunately, in this short webinar, we don't have time to really explore how do you go about developing relationships for somebody who doesn't have nonpaid relationships in their life. And that really becomes the challenge, we have to start looking to former staff, perhaps former neighbors, former schoolteachers, former friends, other relationships that may have existed in someone's life, but may not exist. Now. We really have to encourage those and sort of work to re nurture and re-engage those relationships. I'm going to stop there, and I'm going to get ready to hand it to Mary Beth. Thank you.



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Mary Beth Lepkowsky 20:57

Thank you, Leigh Ann. And good afternoon, everyone. My name is Mary Beth Lepkowsky. I'm a co-facilitator today with Leanne. I'm a white woman with shoulder length, gray and brown hair. And today I'm wearing a dark blue top and behind me are bookshelves arranged by color. So, it's my pleasure with that launching off point from Lian. It's my pleasure to invite each of our panelists to briefly say hello and introduce themselves. And then after that, we have some questions for our panelists. So, Alva, would you, would you please join me in, put your camera on and you can be the first to introduce yourself and just share briefly what your role is, and your experience related to this topic of choosing a healthcare power of attorney.

Alva Gardner 21:50

Definitely, thank you. Hello, everybody. My name is Alva Gardner, and I am a white woman with shoulder length brown hair that is pulled back in a ponytail. I'm wearing forest green glasses and a baby pink satin button-down blouse. Behind me is a blue background through which the handles of my wheelchair sometime come into view when I shift in my seat. And I am new to the conversation and process around looking for and choosing a health care power of attorney.

Mary Beth Lepkowsky 22:48

Thank you, Alva. And Alva, you can take a break from your camera, and we'll invite Deja to say hello.

Deja Barber 22:59

Hi, I'm Deja Barber,

Mary Beth Lepkowsky 23:01

Did you want to put your camera on please? There you are.

Deja Barber 23:06

Hi, I'm Deja Barber. Visible representation of myself, I'm a black woman, 28-year-old woman who is currently in her bedroom, sitting beside a window and you may see a pink wall behind me. And I'm also going to see if you see the blinds move and shake that's because we currently have a thunderstorm outside my window. That's why you might see the blinds move a little bit when I'm on camera. But I'm here today, I'm here on the side of being a minority and talking about what health power of attorney looks like on our end, and how we feel about it, what the data says, what statistics are like we're making a new specifically and just how that works within our families. Which I'm also like Alva, bringing the power of attorney stuff as well, it'll be interesting. Thank you.

Mary Beth Lepkowsky 23:53

Thank you, Deja. We look forward to hearing more from you in a minute. And Shana, welcome you to our panel. And Shauna, just let us know your role and your experience related to this topic.

Shawna Hall 24:06

Okay, thank you. I am Shawna Hall. I am a white woman, and I am wearing brown glasses. I have brown shoulder length pair that's pulled back in a ponytail. I'm wearing a back brace and I'm sitting in a wheelchair with hot pink rims. Behind me is a blurred background with a tan wall and a mirror with a dark frame around it. And I have had two very different experiences with power of attorney and medical



care decisions. One was as a brand-new adult at 18. And one was just recently with a new surgery. So, I'm glad to be here.

Mary Beth Lepkowsky 24:56

Thank you Shawna and we also look forward to hearing more from you in a few minutes. Alva, I'm going to, if you'd be willing to go first, if we can begin with you, we can welcome you back. There you are, wonderful. So, Alva, when we spoke a few weeks ago getting ready for this webinar, you share that this, you know, the idea of a healthcare power of attorney is new to you, and that no one has ever talked to you about identifying a healthcare power of attorney. Can you share more about that?

Alva Gardner 25:30

Yeah, definitely. So, um, I've been a service recipient, since I was six months old. And it was not until I turned 18, my case manager from the regional center, during my first-year annuals, post 2018. In one of the checklist items on her list, asked if I wanted to create a will and designate a power of attorney, and pretty much asked it just like that. As a newly 18-year-old adult, who was preparing to move out of the house for the first time, I was studying college as an undergrad at UC Berkeley. And living in the dorms. I was single, this thought of having a will having designated power of attorney was really the last thing on my mind. And definitely the last thing on my list. Right? Again, I was adjusting to moving out for the first time working with personal care attendants. Full time, for the first time, I was still covered under my mom's health insurance, even though I was 18. Because I the employee of the county, I was able to stay under her coverage. I'm past 18. And so, it really didn't make sense to me in that moment. Why I will prioritize. Fearing will designate a US Attorney, etc., etc. And one of the things, one of the biggest reasons why he was is that, you know, again, when my case manager brought it up, it was really brought up as a checklist. Question there really was no conversation around the implications of having designating a power of attorney, there was no conversation around what it's like, well, I would want to think about designating that person we're starting to have a conversation around creating and will creating an advanced care planning document or anything like that. So, because the lack of that context, coupled with everything else I just sent in, which felt like a much bigger deal. In that moment. It really, in my mind, de prioritized moving forward with that conversation in that moment. And interestingly, it's never been brought up that I'm 32 years old by my case manager it's never been brought up by the case manager.

Mary Beth Lepkowsky 29:46

Yeah, thank you all but you know, you speak about I think some something that so many people experience at a young age not feeling like this is relevant or not needed. At a young age someone who's young and healthy? And then your point about the checklist, you know, the checklist one time at age 18. And never again, and with no context is really powerful. And I think an important reminder to all of us that the people who are inviting the conversation to have some understanding of what that conversation is going to entail. Thank you. You know, we also spoke, or you also mentioned, when we spoke earlier, that you may be in the role of the healthcare being a healthcare decision maker for your husband. And you had some concerns about if and how others will listen to you in that role. Is there more you'd like to say about that?

**Alva Gardner 30:57**

Yeah, just before I enter that, I just want to add to my previous intro, a lot of the information that I am receiving now is mostly coming. Because I know we're in the disability services field. So, I was a, I used to be a direct to professional, I now work as, like I said, as a disability consultant and, and working with drug support professional, and in the disability services industry. And so, almost all of my education and awareness around these topics has come because of my professional role in this industry. Not from my position as a recipient, even though.

Mary Beth Lepkowsky 32:15

Yeah, yeah, thank you. So, you have the inside scoop if you will. And that, you know, that does beg the question of how readily available information to the general population, and in particular people who live with disabilities. Yeah, thank you.

Alva Gardner 32:33

So yeah, so John.

Mary Beth Lepkowsky 32:37

Thank you. Yeah. So, talk about you being in the role of the healthcare.

Alva Gardner 32:43

Yeah. So, similarly to my students when I turned 18. You know, the thought of me being the decision maker for my husband, should something happen to him, and was, although not on front of mine, for me until Leanne reached out to me a couple months ago, and asked me to participate on this on this panel. And as part of that conversation, she brought up some that she knows. And then they get the details of this run, both feminine, she knows who has a disability and has, like me a speech impediment, and is married. And he was sharing with her that he was concerned, that if something ever happened to his partner, that even though they had designated him as their power of attorney, that the hospital or the medical professional, would not believe him and would not listen to him. And I had this spirit of self, let's say, I had this holy crap moment when she said that, but I realized that it had never hurt me that I may experience that scene. Discrimination if I was ever in that situation with my husband. And so that really got me thinking around, you know, what would I do? How would I go? Etc., etc. I'm talking with my husband, and we actually were talking about this morning and thinking through, like what we want to do in that situation going forward. You know, I, I've been fortunate enough that the one time we, he and I did experience a very mild version of that situation. A couple years ago, he was dealing with medical issue. This was before we were married. And I, luckily, I was believed by the hospitals. That was his scope and, and they respected my position in that in that role in his life. But recognizing that medical situation in the grand scheme of things was pretty mild, and it was planned, and it wasn't an emergency situation, it again, still got me thinking of like, okay, what is it was a real time emergency? Would they believe me, you know, my speech, in the grand scheme of things, is pretty mild. Would the hospital staff take the time to listen to me and recognize that most speech impediment is relatively mild, and that they can understand me if they take the time to do so. Um, another element in my situation is that Luca's mother and who I think, like smena, and you know, is it's respectful. But I do wonder if it came to that moment, if and how much, she would respect me as that decision maker for my husband.

**Alva Gardner 37:45**

And that's, along with medical professionals, if it were an emergency situation, you know, her role in interaction is one that I can definitely see why having a designated document that lists me as power of attorney and decision maker would be necessary. And just really quickly, the other thing that we talked about, that goes one step further. So, I've certainly who uses a wheelchair, I'm also very cognizant in an emergency situation, should my husband need to get taken in in England, for example, I can't get into an ambulance. If I'm in the passenger seat. I also don't drive myself into thinking about how would that work? If he didn't need to be taken in an ambulance? How would I get to the hospital? And then one time is there? Would he be in a room that was really accessible? Would the room have enough space for me in my chair, along with of course, all of the medical professionals taking care then, and you know, that added there with all of that hubbub going on all of the injustice going on? Would they can continue to listen to me and involve me in that situation.

Mary Beth Lepkowsky 39:57

Thank you so much. Have a You know you, it's just a strong reminder that you give us about the biases that continue. And what you brought to that conversation was not only within the support community, the healthcare community, but also with family and friends, perhaps. So, thank you for sharing that perspective and also raising the questions about what supports are needed to make sure that in that role, your accessibility needs are addressed as well. So, thank you. So, Alva, we're going to hear from you again in a few minutes. So yeah. And we're going to hand this over to Leanne right now. Deja.

Leigh Ann Kingsbury 40:46

Thanks, Alva. Thanks, Mary Beth. Just wanted to let folks know, the document that Saska has shared, which is the default surrogate consent document comes from the American Bar Association Commission on Law and aging. It's a really helpful document talks about every state that has surrogate decision making laws and what those laws are, you should also know that it is written in full legalese. I am not an attorney. So just take that know that as you're looking at it, if you are not an attorney, and you're working for an organization, you may want to engage your attorneys in being sure you understand that document correctly. We've also been answering questions, but I'm not sure there's going out to the whole group. So Saska and I are talking behind the scenes here to get those answers to some of the questions that came up to try to get those to the group. All right. Deja, thanks for hopping on here with us today. We really appreciate it. So, when you and I first talked about this webinar, and your interest and willingness to join us, one of the conversations that we had was, you talked about the experience of your parents making a decision for a family member. And the observation you made was lots of people, potentially lots of people weighing in on a decision, some confusion, it felt a little chaotic in the moment. And I was just wondering, kind of your experience and your advice on how do you how do you help that scenario? In that kind of scenario? How do you help things not be so chaotic and confusing?

Deja Barber 42:27

Well, in that situation, I figured out that I don't want it to go that way with me, and my children and my future husband, because it just turns into a whole emotional field, where not the best, like logical decision is me. So, the way I would like to see that would be, I would say honestly planning, making a one definitive person, or a couple of different people be the one to say, okay, we're gonna come up with



the plan, we're gonna all agree on this plan. But the point is, there has to be a plan before something is ever made. Because I feel like oh, I Michael dripper, per se, due to religion ended other purposes, we kind of just rest and matter. And we want to fix it right then and there. Instead of just really thinking about a situation. We're like, okay, we gotta fix it, they gotta get better. Okay, they get better with this, like, are they really, so it's like, in planning it, you kind of have to decide, okay, I'm gonna let this person the entirety of this, this person, the entirety of that, and then they'll have to come together and just do it, because it just turns out to be a whole whirlwind of emotions, and not really a good decision to make.

Leigh Ann Kingsbury 43:40

Thank you, that's such an important component of the conversation, is that that emotion that comes into play and, and trying to make decisions at the 11th hour when somebody you care tremendously about is critically, ill possibly really sick. And there's a decision to be made. And you yourself are anxious, worried, and stressed. And so, I think that that is great advice, that idea of planning, and really saying, Look, you're in charge of this, and you're in charge of that. And, and I'm going to trust you all to do that, which must you all to take those roles. You know, I would add also that the other thing that you've really brought up there is the importance of making sure that folks are on board with that, because it's possible, you could identify somebody to make a decision or ask them if they would make a decision for you. And they would say, "No, no, no, I'm not, it's not something I want to do." So, another good reason to not do that at the 11th hour. That is very true. And, you know, part of the other conversation that you and I had was you mentioned to me that you live with a chronic illness that you live with diabetes. And I asked you if you had ever had any of these conversations with your family and given your experience of living with a disability having a what you had identified as a chronic illness. Can you tell me a little bit about that share with us?

Deja Barber 45:04

It's funny Leigh Ann actually asked me to talk to my parents about it. And I didn't do it. Reason why I didn't do it is because I didn't know where to start. I mean, it's kind of a taboo sort of topic. And I wrote to say, hey, who's gonna decide who's gonna save my life, basically. And that's kind of how our world sees it, of who's gonna save me. So, it's like a prime example of my mother, or my father, or both of you can come up with the same solution. So, it's kind of the point of I didn't know where to begin. Because you don't know if I didn't have the same side to start with. And it's just, it's just a topic that, you know, being 28, I'm not thinking about just like almost said, I'm not thinking about my intellect decisions, even though diabetes can potentially in my life, at any point in time, we're making me really sick to where it could possibly in my life, it's just not something I think about. And I'm thinking my whole family honestly didn't even think about it. We just kind of just go with the moment, say, okay, we'll fix it, they'll fix her. We're good. But I think it's just the point of, I think knowing where to start, is a good start to have over even have the conversation. And also, like I was saying earlier, I'm personally what's the plan, so I'm gonna bring up some to them, I want to know what I'm gonna bring up, I want to know, who's gonna sign where what the information says, like, we're gonna know everything before I assume, well, who's gonna find life at this point. And it's just the point of, I think, especially when it's direct relatives like family, I feel like it has to be a really have needed conversation, but it will be honest and true conversation. And I feel like, it can just be very opinion based. And it's not really factual base. And I kind of want to make sure before that, whatever that personally that I know what I'm talking about. And



they take me seriously the notes of the series matter. Because I feel like once I have kids and a husband a little different, but when it's with like, direct illuminous, and raising your whole life, that they can turn into, oh, I'll just take care of you, oh, you're good. You never ever get that choice. Anyway, we're not letting that happen to you. But it's coming, turning into my choices, the problem of concern area, I think, want to talk to them. More about that is one area concern I had, making sure it saves my decision or my choice, and attend to other people's opinions and emotions involved.

Leigh Ann Kingsbury 47:34

Thank you for your input on that. And your advice on that. Insights, which was what I was looking for, you brought up something that's a really important piece here that I don't think we've talked about, and that is that advanced care planning has sort of been couched or always connected to end of life. And in fact, you just said very clearly, you know, at 28 years old, I'm really not prepared to think about end of life, even if diabetes has some impact on my health. And so, one of the things that we often suggest to folks is, is to think about, it's really not about end of life. Until it is and it may be some day, but early on, asking a 28-year-old to think about what he or she wants at the end of their life, when that's not the situation they're in is almost an impossibility. And so instead just saying, no, who's my backup plan, if something if somebody had to make a decision, and I couldn't, who would I trust to do that? Not related necessarily to critical illness, not related to a life ending illness, but just something much simpler, you know, a crisis with your diabetes. And you know, you're not thinking clearly or, or, or perhaps a clinician not thinking clearly. And that's a different a whole nother issue. But I think you really make a very important point there and distinction there that it's early in life, it's very, very hard unless you are living with a diagnosed life ending illness, it's very hard to think about that. So. So the recommendation of horses back away from that end-of-life conversation and just think about who could be there for me if I needed them.

Leigh Ann Kingsbury 49:21

Again, as you just said, in that sort of in the moment, space...

Deja Barber 49:25

...is a symbol of who knows when medication this I didn't like when you think about this, who knows on medication lists, nice and simple that to say like just the basics of our health, as our medical records is important, too. So that will be a good start as well. Medical records

Leigh Ann Kingsbury 49:42

And I'll end with again, Deja thank you so much for sharing your experience in that and your, your thoughts around, you know, having or not having this conversation right now with your family and the cultural impact there of that you in most states, parents are included in the surrogate decision-making hierarchy. And so if you've not had for Deja, or for anyone who's joining us, if you've not had a conversation with someone about being your decision maker, and you're in a state where a sibling is part of that hierarchy, or parents is part of that hierarchy, then know that you have somebody identified by law, who can be your decision maker, as you said, Deja, are they making a decision? Are they making my decision? Right? Are they making a decision that I want them to make? And that really becomes the crux of this is that person aware of what you want and what your values are? As those



decisions are being made? So, data Thank you very much. I'm going to turn it back to Mary Beth. So, we can hear from Shawna.

Mary Beth Lepkowsky 50:57

Thank you, Deja, and Leigh Ann. So, Shawna, welcome. And so, Shawna, your experience is a little different. So, when you shared in your intro that you actually sought out on your own a power of attorney when you turned 18. So, I think we're dying to hear about that. Whatever you're willing to speak to and, and how you chose the person who became your health care power of attorney at that time.

Shawna Hall 51:27

Absolutely. And I appreciate the chance to share because I think it's important. My first experience with Power of Attorney definitely illustrates that it's not always tidy. The first, when I was 18, and went to college, I ended up being forced to leave home quickly because of safety reasons. And so, I sought out a legal power returning on my own for medical decisions, for safety reasons. And again, not in the life decisions, necessarily, but I knew who I didn't want, making medical decisions. And so therefore, I wanted to choose who would be making medical decisions in the event of it was in a crisis. So, and, and I was, even though it was a crisis, I was 18, just like Alva and Deja were at one time, and I'm not necessarily wise, but moving quickly when I needed to. And I went to the people because I knew it would be more affordable than seeking out an attorney. And it turns out that I chose my I chose my power of attorney at the time out of the people who are surrounding me, and a couple who was great support during the crisis. And so, it was just like, oh, my gosh, thank God, you're here. Here's what we need to do. And, you know, maybe we can have conversation later. But thank you for being willing to do this for me at this time. So that's kind of what it was. And for me, it did work out. I would say, the area of medical decisions was the area where I felt most vulnerable. And most at risk. I felt very, you know, vulnerable for some of the reasons that Elvis shared, if I get into medical situation, are they going to listen to me? Or are they got to go to a family member who isn't necessarily a safe decision maker. So, whether it would have worked or not, or whether it would have been honored or not, it provided me a rock. And it made me feel a lot better. And it was something I couldn't do in a situation where there was a ton I couldn't do.

Mary Beth Lepkowsky 54:03

Thank you and you, you remind us of the importance of choosing who we do want to be in that role. And also identifying who we do not want in that role should the surrogate decision making, you know, hierarchy come into play at some point in time. So, thank you for that, for sharing that consideration. And also, you know, it sounds like the people that you chose were in were part of the crisis they were part of helping you through that crisis. So, the element of, of trust, I'm assuming was there and that's, that's definitely connected to the data that Leanne was talking about earlier.

Shawna Hall 54:46

Yep. There was definitely the trust there and it was a gut decision.

**Mary Beth Lepkowsky 54:51**

I got decision. Yeah, yeah. Now your life has gone on and on you recently, within the last several months, named a new healthcare power of attorney or updated that information as you were preparing for a recent surgery. So, can you speak to that? And also, if you're willing share your experiences about the surgery and recovery and in what was having a healthcare power of attorney was helpful or brought comfort to you? Through Okay.

Shawna Hall 55:28

Absolutely, um, the end of May, I had major surgery, but in my point of view, it was miraculous and weighing. So, it was a good thing. And I'm an inch taller. But it did give me an opportunity to look at the power of attorney issue again. And I chose the same people who are who has functioned as family and parents for the last 30 years. But we updated some things. And it was a completely different experience, it was so nice to approach them in a manner of is this something you would like to continue to do? Rather than here we are in a crisis helped. You know, and of course, both of them kind of looked at me, like, you know, well, what are we gonna say? No. But nonetheless, for me, it was important to offer an element of discussion was just so healing, I think, for all three of us. Um, in regard to the surgery, the surgery went great, but, and two days later, I ended up needing blood. And I have never had the experience before of not having enough blood in my body. And I remember just feeling totally just, you're there, but you're not there. It was like being a blob in space, I was also in an incredible amount of pain. What I remember thinking, at that point, there was, ah, these are the situations that those power of attorney conversations are for where I'm here, but I wouldn't be able to communicate for myself. And it just gave me so much comfort. And again, that cushion of safety. All I need to do here is the patient. I can go to sleep, and absolutely trust that, if anything happens, decisions are being made by people who care for me, um, you know, would move mountains for me if need be.

Mary Beth Lepkowsky 57:53

Thank you, Shawna. Yeah, what, uh, what do you need, personally, you know, these perspectives of the first time in a crisis and the second time by choice, you know, by intention and choice. Have you had that second experience? So, we're going to invite our other panelists to join you. So, Deja, and Alva, if you'd like to join me, we've got a couple of questions that we like to invite all of you to respond to if you'd like to. And Shawna will continue with you for this first question. And, you know, all of you, in some way in your comments mentioned about the importance of choosing someone who knows you well. Know, Deja, you talked about some of the least he knows my medication list, you know, and, and a couple of you mentioned trust so. So, someone who knows you well to make healthcare decisions for you, what if you're not able to do so for yourself at any given time? So, I'd like to hear what suggestions do you have for service providers about how they can help people with disabilities who may not have a natural go to person in their life? So how can service providers or people who are in direct support roles, help people to build relationships and maybe find they're who that might eventually serve as a healthcare power of attorney.

Mary Beth Lepkowsky 59:28

So, Shauna, would you like to respond first?

**Shawna Hall 59:31**

Yes, I think that service providers could help. Since it's such a touchy issue to begin with, maybe start with a person by saying what things would make you feel safe in an emergency situation are who are the people in your life who make you feel safe, whatever's going on? Who are the people in your life that you trust? I'm start that way; you start with small questions that invite conversation. And if they don't have anybody, which is unfortunately often the case, hopefully those questions will provide both the service provider and the person ideas of what kind of person they're looking for. Start small. Yeah.

Mary Beth Lepkowsky 1:00:23

Great suggestion. Thank you. Alva, how about you?

Alva Gardner 1:00:27

Yeah, so for me, it's two things. First, it's bring it up more than once. Don't do what happened to me. You know, bring it up at 18. And, if and when the person inevitably said, I think about that, right now, you speak to it in both larger context of family life, I work in person centered field, and I recognized with the shift in this field toward more person centered and hopefully, this will become more par, for course. But even when, even if your agency or organization is not the person-centered crane yet, which it shouldn't be, but if it isn't, yet, at least framing this conversation, in that larger context. Here's how, how having this in place will affect you, and your life holistically. And then also, having at least something as a resource to give somebody to initially start that journey. So, whether it's a resource list that you just hand out, that has in warriors, river, see, I still don't even know who would be the person that that individual would go to. And if it's more than just be able to see that conversation of what the process might look like, and who somebody can go to start that.

Mary Beth Lepkowsky 1:02:51

Thank you, Alva, and Deja. Is there anything you'd like to add? Yeah,

Deja Barber 1:02:55

I can piggyback off as well. I would say that also just not even just giving resources, have somebody if you are healthcare service office, which can come talk to them what that means, because we've all been in the hospital and ask, do you have a will? Do you have an attorney, but she wouldn't know who that person was? I don't know what that process even looks like. I don't know what the words mean, they don't know anything. So, if you have somebody there, that job is to just say what that means. Not even just planning it out, because they might want to point it there, but they might not. But the money that gets the conversation going, where they know what's going on. It's not no first decision making, but even having to use a surrogate decision making may lead that day. And then like, you know, I'm gonna start this process tomorrow. So it's the one that two I would say, there's one thing and the other thing would be, I guess, just to have an honest conversation, I feel like we kind of ignore this a little bit, because we're fighting it all back to us or relating it back to a certain age demographic, instead of realizing it's important for all of us. And as we noticed the age, the age, the age range for death, it's getting lower, so we can't fit it all in one demographic range. So, starting the conversation earlier, are awesome kids.

**Mary Beth Lepkowsky 1:04:14**

Yeah, what a great reminder, thank you for that. And, and yes, when we when we do workshops around advanced care planning, we, you know, we suggest anybody who has a driver's license or a driver's permit, it's a good idea to start identifying, you know, healthcare power of attorney, because you just never know what's going to happen. Right. So, you know, one thing that I would add as a tip or a suggestion for service providers, and then Liana, I will invite you to share if there's anything else you want to add is not to rely on the here and now. So, look beyond the people who are in someone's life today. I am couple years ago I was planning with I was facilitating person centered planning with a man. And he, he had he invited, he was probably in his mid-30s, I think. And this was general person-centered planning, it had nothing to do with advanced care planning or care at end of life. He was he was young and healthy. But he invited he wanted to invite to his person-centered planning meeting a former teacher. So, he hadn't been in touch with this man for 20 years. But he sent an email, he got in touch with them and say, hey, you know, I'm bringing some people together, I'm going to be thinking about what I want to do over the next year or so. And we'd love to have you join us. And the teacher came, never been through a planning meeting before. So, he sat through that process. And at the end, when you know, everyone shared their, you know, wrap up appreciations. The teacher spoke and said, this was an amazing experience, it was a great use of my time. And I'll call this man, Keith. He said, "Keith, I want to continue to be part of your life." So, what a huge surprise, so they've continued to be in touch. And that's a relationship that didn't exist, it wouldn't exist on his relationship map if you're familiar with Person Centered thinking skill. But it was a new relationship. That was a reconnection from the past, which could certainly develop over time into perhaps that trusted decision maker. So don't limit us to the here and now. That's going to be my tip. And Leanne, anything you'd want to add?

Leigh Ann Kingsbury 1:06:55

No, I think, I think not just the hearing that I would add to that not limiting to hear now. From a service provider standpoint. You know, I think it does, this is a this requires time, it requires intention, it requires that we, that we find out if somebody doesn't have somebody in their life right now that that makes sense, or that they would be comfortable with or that is not in a paid health care role. It really requires intention on our part to say, who used to be in your life? Who did, who provided supports to you previously, that you had a relationship with that you really liked spending time with it, like spending time with you? I remember planning with a man many years ago, who had a level of challenging behavior and, and we were able to find staff that he worked with him 10 years prior to kind of the crisis that he was in at the time. And we actually found former staff who said, I loved him, I loved working with him. And no, it wasn't about power of attorney. This was a group of people who had a whole different view of what life could look like for this gentleman. And their information was priceless, and helping this guy, you know, kind of reclaim a really meaningful life. So, I think that's, that's a really critical piece. I think the other thing I would add is if as a provider, if you are state rules, if you are a provider of services, and you obviously have disability rules to follow. And if one of those rules says, you know, you have to ask people if they have advanced directives, it's much, much more than yes, no question. And it's much, much more than a checklist. And I think that's what happens often is that, you know, the forms that we fill out are the fields that we have to click on the computer say, Does the person have advanced directives? Yes, no. If the answer's no, do they want them? Yes, no. But our experience, certainly the experience, Mary Beth and I have had in in training this for many, many years and teaching this is if the



answer to both those questions, if the answer is no, I don't have advanced directives. And then, you know, I'm not sure if I want them or the person is not sure. Her experience tells us that people aren't quite sure what to do next. As Deja said, how do you start that conversation? What if it's not about end of life don't start at end. So, you know, that really becomes kind of the next piece for providers is helping the planners, the folks who are required to do planning, they may be case managers, may be care coordinators, maybe care managers, lots of different terms there. But helping those folks really get anchored in, in practice and comfort and feeling capable and competent and their ability to help someone develop their advanced directives.

Mary Beth Lepkowsky 1:09:46

Right. Thank you. So, thank you all. So, the next question we have is and Deja if it's okay, well, we'd like to invite you to start because you mentioned this, you touched on this a little bit when you were speaking earlier. And could you comment on you know, in what ways has your culture your identity, spiritual beliefs or any other dimension of diversity shaped your thoughts on this topic? Um,

Deja Barber 1:10:15

As I've said earlier, I think if there's something, say, as a black female that we kind of, don't talk about it, it hasn't changed my viewpoint and not wanting someone get up and discussion. But it does bring overalls to overalls. And not it. I do think that like, it's just awful, I'm in the south. So, I gotta bring that up, one off. Now I'm in the Deep South, and we believe in our spiritual beliefs and kind of focus on that a lot. So, it's just a lot of, also we live at the environment, you're from the family situation you grew up in, like it shapes and shapes, I can't really want to bring it up. But we just don't know how. And even if we knew how everybody is okay, with bringing up I think is the biggest issue and training could be better brought on that topic. And I feel like it's like something we just even did bring it up. How do we handle the emotions around bringing the topic up?

Mary Beth Lepkowsky 1:11:16

Yeah, thank you for that important reminder for all of us not to make assumptions that you know, it's sort of an interesting contract contradiction, I guess that there are more and more, my experience has been more and more healthcare systems. I'm connected to a number of hospitals in our area that require this advanced care directive, I'm sure for health for insurance and liability reasons. And yet, some people just really don't, it's not part of who they are, to, to have these conversations and to do this bit of work. So, a good reminder for us all. Shauna, would you like to comment on that question?

Shawna Hall 1:12:02

Sure, um, there's three different things that came to mind right away when you ask that question. And one is my experiences in the medical community that shapes a lot of my opinions, and it is culture and that doesn't mean it is part of my culture growing up, that doesn't mean it was good, bad, or indifferent. It's just part of it. The other one is that my spiritual beliefs are very important to me. And they shape a lot of my other decisions about things and so be very important for my person tend to know that and know how it shapes my decisions about healthcare. And I had one other one, and it completely went off in my head. But I'll, I'll sum it up like this. For me, you know, my biological family was not safe. And that's a hard thing to say. And I don't I don't advocate just grabbing a new family if your original one doesn't work out. But what I do want to communicate is that it's important for caseworkers and people



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in the medical field and even daily help to remembering keep it in mind, not to automatically assume that parents or siblings or whatever is the is the go-to, but check that out. Just check that out. Because it can be really tender to have to advocate about as well.

Mary Beth Lepkowsky 1:13:36

Thank you, thank you, but a great suggestion. And Alva How about you? How has culture identity beliefs shaped your thoughts?

Alva Gardner 1:13:47

So, from the perspective of culture for me, in this context, meaning being a service team to for my entire life. And I said you Well, I'm very grateful for the services that I receive support today. But I've also had to fight through this system or a lot to fight against assumptions being made without the, the service system that is there to support me and as such, I've and still to this day, I very much limit the amount that I am dependent on the service system. I limit You know, the information that I tell my service providers and my support providers, because I do that very much because I bucked the system assumption into just because we had disabilities, which gives them the right to know, every in and out about life. And well, that might need to be the case, in some situations, I don't think that should inherently be the default or the assumption. And so, because of that, I also believe, don't actively reach out to service providers to ask for services, or explore what they can and can't provide, because I am wary of opening the door.

Mary Beth Lepkowsky 1:16:23

Thank you. Yeah.

Mary Beth Lepkowsky 1:16:24

It's a good reminder of, to remember the respect and humility and of, you know, that is needed when, when being invited into someone's life. And I love how you said, you mentioned that about not making assumptions that we have a right to know everything about a person. Thank you. So, we have one final question for all of you. And this is really an invitation for each of you to share one tip, one top tip, or piece of advice that you have for others who are just getting started with thinking about identifying a healthcare power of attorney, or completing an Advanced Directive, what's your top tip? And here, we'll start. We'll start with you Alva, and then go to Deja. And Shawna. Sure.

Alva Gardner 1:17:20

So, I touched on this a bit earlier. But it really is no know, to ask somebody, if they want support around advanced care planning and supported decision making. And know, to ask, to tooting know, to ask multiple times, don't just bring it up once and never again, and know to ask and frame the question, again, within the world or context of somebody's life. To that they can draw that connection between sending that when you first bring out is very foreign, it's very nebulous, and doesn't necessarily unless it goes to an emergency situation doesn't really hurt all of us. But within the context of our wives, is going to hold a different way.

Deja Barber 1:18:40

I guess I'll go. My long, deep move. My one tip would be don't run into stupid, because I felt like I'm at this point now after multiple conversations, that I feel like need to stop running because it's important



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for everybody to do, regardless of disability or age or anything. We all kind of make that decision. So just don't get it done.

Mary Beth Lepkowsky 1:19:07

Thank you, Deja. Good advice. And Shawna.

Shawna Hall 1:19:10

Yeah. My top tip When beginning to think about who your person might be is think about who knows you well. And also think about who has a level head in a crisis?

Mary Beth Lepkowsky 1:19:27

Yes, great top tips. Thank you. So, Shawna, Alva, Deja, thank you all very much for just sharing some intimate parts of your lives with us. We feel honored and you had some vulnerable conversations there. So, thank you, Leigh Ann, and I'm going to hand it over to you and Alixe to field, we have probably a few minutes to field a couple of questions from chat.

Leigh Ann Kingsbury 1:19:56

Thanks, Alixe. You know, we had a text message going about a couple of questions that kind of keep resurfacing, resurfacing been trying to answer them as we've been going along. But...

Alixé Bonardi 1:20:10

Thank you. Thank you all for all the participants, and also everybody in the audience for your really engaged conversation that's been going on. We have just a few minutes. But we do want to take a minute, Leigh Ann, thank you for responding as much as you can, and to our folks in chat who have actually been sharing resources and connecting. One question that kept coming up in a number of different ways is around an interest in having an organization or a professional service function as healthcare power of attorney. And I just wonder if any of you have any insight in that?

Leigh Ann Kingsbury 1:20:53

You know, this has really challenged me to think, have I missed it? I have not heard of any kind of national organization, recruiting, for example, you know, people are members who would serve in that role.

Leigh Ann Kingsbury 1:21:17

And I feel a part of me says, interesting concept, part of me thinks of all the risks that go with that. But the short answer is I'm not I've not heard of that existing. A couple of folks did ask if organizations could serve as power of attorney. Again, my, my understanding, in my experience is that organizations do not serve. For example, I'll use an example. We know that sometimes folks have Public Guardian. So, the Department of Social Services in some counties, and in some states will serve as usually the director of that department is named as the guardian. And then there's a guardian representative on staff. We know of certainly guardian ad litem; I've not heard of that kind of process existing for healthcare power of attorney. So that's the short answer. I would just reiterate, a couple of folks also talked about how important it is to recognize that power of attorney conversations are not one and done. And that's absolutely spot on. And the decisions that you make now are the people that are involved in your life now. Or perhaps that as Alva share, I'm sorry, I think it was Shawna who shared a story about that.



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People that you designated 10 or 15, 20 years ago, may still be in your life, and you might want them in that role, but maybe not. So, these are really ongoing conversations. The last thing I'll say about that is the counter to that is, I would caution us to not just roll this into again, from a service system, provider system standpoint, I would not just roll this into Oh, at the annual planning process, once a year, we talked about advanced care planning also, it becomes then a checklist process and this is a much greater conversation review.

Alixé Bonardi 1:23:19

So, appreciate that Leigh Ann, the word conversation, if I were to count, the number of times conversation came up in the context of in this last 90 minutes. It was many, many. And I think that that is something that that is really important to remember that it is a conversation that happens again and again. And we heard that from many, many people. In chat. We've seen a few people providing in some examples of folks in their own communities that they have seen anecdotally who have stepped up in some cases to serve as healthcare power of attorneys. And I think going back to something that that you noted a lot earlier. Leanne, I think around discovery this that you commented in chat, there were a number of questions about well, in the cases where people have a heart don't have an easy answer to who are the people that you trust. This becomes a process of discovery and even reiterates and underlines the importance of spending time to think about relationships and the conversations and the relationships that people are building over time. What wonderful conversations that we all have had in the last couple minutes that we have. I'd like to ask Leigh Ann and Mary Beth if you have any final words for the audience here

Mary Beth Lepkowsky 1:24:58

You know, I think Yep, yeah, actually, given the time we have I think the final thoughts that we had had were all have already been spoken so eloquently by our panelists. So, I think we're good.

Alixé Bonardi 1:25:10

Wonderful.

Alixé Bonardi 1:25:11

Thank you to you all. Thank you to our facilitators, Leigh Ann, and Mary Beth, and particularly thank you to our panelists today who really brought forward some really important and really essential elements of advanced care planning. Dasia, Shanna Elba thank you to each of you, for your own unique and important perspectives. With that, I would like to ask those of you who are with us still in the audience to complete a quick real time evaluation of this webinar. This is an opportunity for you all to tell us how we're doing and please again, note that this is a place where you there's a little gray bar on the side, and you can scroll down to get to all six questions that are here. So again, thank you, everyone, for your participation today. And we look forward to seeing you at upcoming webinars, please make sure that you that you check out our website at ncapps.acl.gov and where we have listings of upcoming webinars as well as resources. And just a reminder that this this webinar, the recording of this webinar, as well as the transcript, responses to questions that our panelists may want to provide, as well as a plain language summary will be available posted on our website there and made available. Thank you, everyone.