



## TOGETHER WEPLAN EP. 3

### Beyond Guardianship: Exploring Supported Decision Making

*With special guests Nina Weiss, Esq., Joseph B. Young, Esq.  
and Elizabeth G. Farishian, RN, MA with host Ellen Nalven*

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Ellen: Welcome, everyone. Thank you so much for joining us today. My name is Ellen Nalven. I'm the Executive Director of Planned Lifetime Assistance Network of New Jersey. And we have with us today three distinguished speakers on the important topics of guardianship, alternatives to guardianship, and supported decision making.

Nina Weiss, an attorney who specializes in guardianship and other matters; Joe Young, an attorney who is the former Executive Director of Disability Rights New Jersey and the Vice President of PLAN|NJ's Board of Directors; and Liz Farishian, who is a nurse and is the President of PLAN|NJ's Board of Directors and also a parent of a daughter with disabilities.

Nina, thank you so much for joining us today.

Nina: Thank you. My pleasure.

Ellen: Joe, welcome. Thank you.

Joe: Happy to be here.

Ellen: And Liz, welcome to you too.

Liz: Thanks so much for inviting us.

Ellen: Our plan today is to talk about different types of solutions that can be used to provide legal, financial, and personal protections for people with disabilities, while at the same time preserving their rights to self-determination to the greatest extent possible.

I think many of us are familiar with the guardianship process and perhaps understand that the necessity of guardianship in some situations is important. For example, when someone has extremely significant disabilities, perhaps they are nonverbal or have very limited communication skills, and they may be vulnerable to abuse, neglect, and exploitation.

Guardianship in these situations may be an important protection, but today we'd like to focus more on what protections for people might be available when full guardianship might be inappropriate? We use the term plenary guardianship, which refers to guardian of the estate and property where most rights to decision-making are removed in those situations.



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We'd like to start and talk about some of the alternatives to guardianship and some other options.

Liz, let's start with you. You and your husband made a decision not to pursue guardianship for your daughter, Vickie. Would you talk about your thought process and what guided your decisions?

Liz: Let me start by saying, I'm rather a proactive person -- kind of a nice way of saying I like to be in control. When she turned 18, I said to my husband, actually even before she was 18, "we need to go to the lawyer and see about guardianship." And he simmered me down and decided that he's going to do that.

We went to a special needs attorney; we sat down with her. I was thinking that - even though she was, at 18, relatively high functioning - that we would think along the lines of full guardianship. We got there and the attorney started asking us questions about her and she looked at us and said, well, she's not going to qualify for full guardianship, maybe limited guardianship.

At that point, Vickie was almost 18. She was starting to learn how to drive. She was no longer in a special needs school. She was in a regular school in a special program. She had an after school job, which she was very capable at. All her ADL's were done on her own, she had a good social network, she went out with her friends, they went out at night, so she was pretty independent.

So we got in the car, and we had listened to the attorney. I said, okay, let's try this limited guardianship, and my husband looked at me and said, no.

He said that one of the other things they had said was an attorney would come to the house and would interview her. And we knew that would be upsetting to her. Even if the attorney was gentle, just the fact that she needed an attorney to come and talk with her would be somewhat of a trauma.

She had never done anything in her lifetime that would suggest her being impulsive. She never acted on anything without consulting us first. So we had no reason to believe that all of a sudden she would decide to sign contracts or things like that. So my husband said, let's wait it out. We'll keep on talking to her, keep an eye on it, but not go on this journey,



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particularly with the fact that limited guardianship, she had already said the courts hadn't weighed in on it yet. And this is talking 24 or 25 years ago. So we decided to not to do the guardianship at that point.

As she got older she became even more independent and clearly showed that she would not make a decision without consulting us. And like her mother and her dad to some extent, she not only consulted us, she would question us as to who else she could talk to if it was something that she felt was not in our area of expertise, much to our chagrin sometimes. So we were comfortable with that decision and have not pursued any guardianship since then.

Ellen: So, that's really interesting. The key for you is that you were assured that she would consult other people if she needed guidance or advice.

Liz: Yes, definitely. And she has proven that. The most recent example was actually yesterday. She's immunocompromised so since then she's developed some health issues. And with the new COVID shot, she had to decide whether she was going to take it or not. Well, she consulted all her physicians. One guy said, "well, it's really up to you." Another one said, "I really think you should take it even though it's not that important, but you're immunocompromised." She asked us, and then she made this decision on her own to get the shot. We said, basically, it's up to you. Your docs have said yes, no, maybe and she decided on her own, but consulted the right people and even her physician said wow - she's really proactive. She really wants to know what she's getting into.

Ellen: So she, like the rest of us, does research and gets guidance that helps her make a decision for herself.

Liz: Yes, and even, despite her challenges, she recognizes what she doesn't know and where she needs help. And I think that's really a clear demarcation of when the need for guardianship becomes important. If somebody doesn't know what they don't know, it's more frightening.

Ellen: That makes a lot of sense. So Joe, even when there is a guardianship, the guardianship law requires that the guardian protect the health, safety, and well-being of a person under guardianship, but it also requires that the guardian promote self-determination of the individual under guardianship. Could you talk to us about that law to help us understand that provision of the law?



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Joe: Sure. To do a little bit of very uninteresting and very dull history, legal history, is that originally, the state - that is, the king - was responsible for taking care of the people in his kingdom that were unable to make decisions for themselves or needed assistance. So now, in essence, the state has delegated as the guardian as the state's authority to do that. So, the goal still is to protect the individual who's not able to make decisions for themselves or good decisions for themselves. But then also the king used to take all the property at the same time. So that's the fear that we have these days, that the same kind of exploitation that may happen.

If there's guardianship, we basically talk about two different kinds of decision making that a guardian is required to make. One is best interest decision making and the other is substituted decision making.

The priority is always substituted decision making. To involve the individual in making the decision. To help them, to find out from them their preferences and a variety of other things and then try to make the decision that they would make. Even if it's not always the safest possible decision, as long as they're not going to be an imminent harm to the individual, generally you try to make the decision that the person would make and involve them in that decision making.

And that accomplishes a couple of things. One, it affirms their individuality as a person, but also it may be helping them make decisions that they otherwise would not be making. If in fact, the guardian believes that the individual's decision that they would make would be an ultimate harm to their health or safety, then you apply the best interest standard and go along with what the guardian believes would be the safest decision to make for that individual.

Ellen: Yes, even if someone is determined to be incapacitated in all areas of their life, it's really important to know that the person does still have opinions and perspectives and choices. It's critical that the guardian understands their obligation to know what the individual would want and not what they necessarily think is best for that person. Right?

Joe: And even a person with severe disabilities who may not have ever spoken or communicated otherwise, if you've been around the person long enough, you know, there are preferences, right? And so you should be facilitating an environment that that maximizes those preferences. Right.



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Nina: Can I interject on that also? A lot of times in the state of New Jersey, the public guardian is appointed for individuals over 60. They're the guardian of last resort. And in that case, the guardian doesn't know the person, but it's incumbent upon the public guardian and their social workers to interview collateral people in the person's life to gather as much information as possible so that they can exercise substituted judgment. You know, theoretically, even the public guardian doesn't just have carte blanche authority to make decisions. They have a duty to ascertain those wishes if they can.

Ellen: That's a great point, and it really emphasizes the importance of having detailed information more than, let's say, the planning documents that we typically use in the field of people with disabilities, but rather what we call a Life Plan that really talks about the person, who they are from a factual basis, but also from an emotional basis - what they want, what they like, what they're good at. A Life Plan really helps to inform future caregivers, because even when there is a guardian, there is likely to be a successor guardian who may not know the person as well as.

Joe: Right. And so what I was talking about was the ideal, right? So that's what's supposed to happen. The concern is that that doesn't happen, right? That the safest move for the guardian is to do no harm to the individual. So we've had clients who've been functioning marginally in the community, doing well if you ask them and talk to them and provide supports. But if a guardian gets appointed, the next thing you know, they're in an enclosed environment, either a group home or a nursing home, where now they're safe, but they're really not exercising their life as they would like to live it, despite the extent that they're actually able to participate.

Ellen: Yes, it's a great point. Nina, I know that you are often court appointed attorney in a guardianship matter. Would you explain what that means? What is your role and why is that important?

Nina: I'm going to jump off on what Joe just said about the ideal versus what happens in real life. Every state is different, but in New Jersey in every single guardianship that's filed, an attorney is always appointed for the "alleged incapacitated person." It's not simple. It's an important due process requirement that the proposed guardian is asking the court to take decision making rights away, so the court appointed attorney is there to advocate for the person.



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In my view, and there's case law on this, the role of the court appointed attorney is twofold. It's to advocate for the stated wishes of the person, just as if Ellen, you had hired an attorney, you would expect that attorney to be your advocate, full stop. It's the same as if an attorney is appointed by the court, you're the person's advocate.

In guardianship, the other role is to the extent appropriate, to advocate for the least restrictive alternative. So, let's say if someone files for a full guardianship, to analyze whether something less restrictive like a limited guardianship or a power of attorney or something like that would be appropriate. So that's my role as the court appointed attorney and I can go into the details.

Ellen: Yes, if you would give us some examples of where perhaps there was a filing asking the court to appoint a full guardian, but you as court appointed attorney felt differently about what ought to be the conclusion.

Nina: I've recently been appointed on a few matters where the person turned 18, just like your other guest said and I think parents are being told by various people, when you turn 18, you file for guardianship. I think that's just what the word on the street is, regarding what to do. So, I guess they hire an attorney.

I actually had one case where they were pro se without an attorney and they filed for full guardianship. They either didn't know about limited guardianship or the attorney advised them there's no harm in the full guardianship, similar to what Joe said. Even if you're full guardian, you can do what they want anyway, so there's no harm.

So that's the theory of when people file for full guardianship. In a few recent matters, I was appointed and when you read the pleadings, the court appointed attorney got a copy of all the court papers. And in the last two filings I had, I'm reading the papers and I'm thinking, wow, the person's very disabled. This is what I'm gathering from the certifications of the physicians, the parent statements. And in the role of attorney, you have to meet with your client and ascertain and file a report with the court of whether this is appropriate or something less restrictive. I met with each person and I hardly even spoke to the parents.

I had an hour long conversation with each 18 year old. Lots of insight, lots of good questions, talking about their goals for work. One girl I interviewed blurted out right in the middle of the meeting in front of her parents "I want to finish school at 18, I don't want to



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go until I'm 21. I'm done." This was news to the parents who always thought she was going until 21. So, these were young adults who probably weren't able to make informed consent and they weren't able to, let's say, manage their social security income, but they certainly had clear wishes and insight about work and about education, which are two hallmark areas of decision making for this young adult population. For any young adult, any 18 year old is not going to be the best decision maker.

Ellen: That's a good point. Any 18 year old.

Nina: So it was in the one matter where the parents did not have an attorney. I spoke to the attorney at the court and her first question to me was - "is your client objecting?" I said, no, he's not objecting. He is diminished. He doesn't know how to object. He's not objecting. But I know that as his attorney, something less restrictive is probably appropriate for him. But he's articulating that in another way. He's not directing me. And I was trying to explain that to the attorney in the office. He's not objecting, and I'm not objecting either, but proposing something less restrictive. So, in that case, the court worked with me, and we hired a psychologist who ascertained certain areas where he was able to maintain decision making and the parents ultimately agreed.

In this other matter I had, we also put through that he retained vocational and educational decision making rights. Because it was similar to Liz's situation. He worked with his parents. He was already 21. He'd been without a guardian for three years. There was no reason to believe he wasn't going to continue working with his parents. It was almost like a fear that they had to get the guardianship through.

And then this other matter I had; they had her pediatrician file one of the certifications supporting full guardianship. So as the attorney, you speak to the certifying evaluator to talk about limited guardianship. No fault of the pediatrician, but he had no idea what I was talking about. He's the treating pediatrician. He's like, "well, mom's going to do what's best." I said, "I don't disagree with you. This is not about mom. This is about Jane and her rights. I don't disagree that mom will do what's best." And I had to try to explain to the pediatrician, but he doesn't know.

I think what I'm trying to say also in matters like this, a psychologist is usually a good person to consult and retain because they're the ones with the expertise to know about areas of insight and decision making. In that matter, the parents did ultimately agree to let



her make her own vocational decisions, but it was a bit adversarial, I guess, at that point, and it's kind of a cause of concern, and the attorney who represented them was a very well established disability attorney.

They filed for full guardianship. People think there's no harm, and I try to explain to them, "as long as you're alive, there might not be any harm, you're going to let her do what she wants, but when you're no longer here and someone picks up that guardianship judgment, it needs to reflect her abilities, because if the state takes over, or if a relative takes over, we need to know what her rights are and what her abilities are."

Ellen: Yes. So say a little bit more about limited guardianship.

Joe: Can I add to this? Because I think Nina makes a very good point that we need to talk about, and that is that the disability advocacy community is light years ahead of where the general bar and the bench are. There was a court case in 1992. The MR decision did two important things: the Supreme Court said you've got to pay attention to limit a guardianship because before that almost every guardianship in New Jersey was a plenary guardianship regardless of how well the person made decisions. The guardian was appointed to do everything. The court said, no, you've got to back up and assess.

Nina and I had a conference shortly after that decision. We talked about limited guardianship. A judge followed us after that, and the judge was horrified that we were talking about limited guardianships. I mean, he was just absolutely horrified that anybody who came in front of him would be allowed to make any kind of decisions.

So I think we progressed a little bit, but not very far, right? I think there's still a tendency among the general bar and among the bench to impose much greater restrictions than are really necessary.

The second part of the MR decision dealt with the appointed attorney. In that particular case, the 18 year old was pretty articulate about what she wanted in certain specific areas. So, she was appointed somebody to represent her. They went in and had a conversation in front of a judge where the judge asked her questions. The judge was not very good at asking somebody with a disability questions. It was like a very poor cross examination, jumping from subject to subject, not following up, all that kind of stuff.





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After that conversation was over, they came out of the chambers. The woman's attorney told the court, "I believe she needs guardianship now. I'm supposed to represent her. She doesn't want one, but I think she needs one." The court said, "You can't do that. You've got to represent the individual."

Less than a year ago, the court did it again. Another attorney was appointed to represent somebody. The person said they didn't want one. And the attorney represented the court. He thought she should have one. So, this is 20-30 years later, and some attorneys - not all - are still doing the same thing. So, the disability community is over here or up here and we're slowly, very slowly pushing the bench and bar in that direction.

Nina: And on that point, I mentioned before we sat down now that there's a form promulgated by the administrative office of the courts. It was a form report for court appointed counsel. In that report, it basically asks, are you recommending guardianship? Why or why not? And I always mark off, I have not ascertained any grounds to oppose. As a court appointed attorney, it's not my role to recommend guardianship or not. I'm a layperson. So how do I know if someone needs a guardian? I'm an advocate. I'm kind of like a stopgap to advocate. So, I always just write in, no grounds to oppose - rather than saying, yes, give him a guardian. I agree. That's not the role of the attorney. So even the report, the form report is really inconsistent with MR because it should really just say, are you opposing or not opposing, not whether do you agree or disagree? That's not really the role of the attorney.

Ellen: Yes. And just explain what you mean by MR.

Joe: Oh, I'm sorry. That's the name of the case. It's initials for the person in the case. The court rules are also not really clear about the role of the appointed attorney. It does kind of indicate that you're supposed to recommend where the person needs, and it really isn't the role. In our role at the Disability Rights of New Jersey, when there was a tendency to put more and more people with intellectual disabilities in institutions, where they're basically not able to make any decisions, very medically involved and stuff like that, we would go out and try, if we could not engage in a conversation or got no response from the individual at all, we didn't say they should have a guardian, we just did not object to the guardianship.



Ellen: Exactly. Yes and that's the role that the attorney should play. So, this is interesting, especially as you talk about the role of the advocacy community as compared to the role of the Bar, and it sounds like we have a lot more education to do.

Nina: And I think a lot of it comes down to the attorneys representing the parents. Because if you think about it, it's a little frightening that the court appoints an attorney, it is the only protection because you don't know who you might get. You might get someone appointed who thinks they're more of a guardian ad litem and more paternalistic. The attorney in the case I mentioned should never have filed a plenary guardianship because when I raised limited guardianship, he didn't object. He's like, oh yes, they almost agreed. So then why did you - then you should be counseling your clients to file - you should ascertain what the person can do or not do, and then get the evidence to support that. Hire a psychologist, get a functional assessment, and then file that. You shouldn't leave it up to the court appointed attorney to be the only stopgap.

Ellen: It's interesting because it sounds like if families are more educated to know what it is they might ask for, they might get better guidance. Liz, were you going to say that?

Liz: That's just the point. Your focus is on the lawyer and the attorney, and my focus is that we really need to educate the parents and the physicians as well. Because for the parents, it's a knee jerk reaction. I've also worked in the field for quite a while, and you meet two kinds of parents. One's that don't even think about guardianship at all, for people who clearly need it. And then if they're in a position where they need emergency surgery, then the doc said, well, he can't make informed consent and the person has no guardian. That's a problem.

But on the other hand, there's also the problem of parents who just assume, I'm fairly well educated, and I just thought, yes, she'll need a guardian. I think we need to also educate parents and whether that's at the educational level, one of the roles that the Individualized Education Plan team in schools has to do.

Physicians need to be educated that there are alternatives to full guardianship and why it's important. I think Nina, you made a really good point. While parents are alive they are going to make good decisions, we hope. One of the questions that I would have too, but to finish this thought first, then who becomes guardian after that? A lot of times they appoint siblings who might have other issues and other motives. That becomes problematic. But



one of the questions I would have is that if you're doing an interview with a client who potentially needs guardianship and you feel that the parents are going to kind of take over and not allow that person to have any input into the decisions, what do you do in that case?

Nina: Are you saying, "the person has, in my opinion, abilities"?

Liz: Correct, they have abilities, and they could have input, but you're sitting with the parents and the client.

Nina: I would insist on a psychological functional assessment because again, all I am is the attorney, so I do have trusted professionals I work with, but if the psychologist comes back and says they can't make these decisions I'm going to have to rely on that, but I would insist on that assessment. And the courts are responsive to that in both these situations. The courts did allow me to go through that assessment. And then the parents ultimately agreed. Or let's say if you just feel the parents are going to run roughshod over a person. Thankfully I've never had that where I don't think the parents are an appropriate guardian.

Liz: But I could see that happening.

Nina: I've run into cases where that has happened. And then it comes very difficult as the court appointed attorney, it's a little lonely of a spot because the person's not objecting. So, they're diminished, they're not going to direct me what to do. Like what the attorney told me when I called, Is he objecting? No, he's not objecting, but I sense that something less restrictive is appropriate. It's difficult.

Ellen: But that's really why that role of court appointed attorney is so important. Especially one who is educated to be sensitive to these issues.

Joe: If I can just interject on Liz's question, the MR case, in fact, involved two parents that were in dispute about who would be the better guardian. In fact, it was clear that the dispute was which parent would allow the child to be an adult child, to be more independent. Fortunately, that was resolved out of court. There was no formal court opinion deciding who would do it.



Ellen: Right. I think these topics of advocacy and the issue of the impact of taking away the vast majority of decision making rights has led to the elevation of the question of supported decision making significantly. And there's a lot more conversation about that.

Joe, I'll turn it to you to understand that when we talk about supported decision making, in some cases, Liz, like you said, "My daughter will go and get help. She'll ask people." So that is a form of supported decision making. But when we talk about what is enshrined in law, what are we talking about? Where is it enshrined in law in what states and what difference would that make? Would that make a difference?

Joe: We may have to back up a little bit and talk about some of the other items. Limited guardianship is an in-between thing, right? That gets confusing to me because the Court Orders sometimes will read that the person has the ability to make simple legal decisions. What's a simple legal decision or simple medical decision? What's a simple medical decision for me? So again, to us, if the doctor's recommending brain surgery, is that a simple or complex decision?

It's complex for the doctor, but the decision to have it, I want somebody to make a simple decision for me to make, right? I once had an emergency medical hearing about a dental procedure. Somebody thought the client needed dental work. I talked to the client on the phone. I was appointed five minutes before the conversation. I asked her, "Do your teeth hurt?" She said, "Yes." "Would you like somebody to fix your teeth?" She said, "yes." "Would you like somebody to fix your teeth if there's no real risk that you'll be hurt more?" She said, "yes."

The court felt that wasn't enough for her to consent to the procedure. I thought it was enough for her to consent to the procedure. So, what is limited decision making? In my mind, that doesn't work. Now it may be in the MR case, there were three things that were essential to her. She wanted to make a decision about where to live. That was actually the most essential.

Nina: Because the parents were divorced, and she was expressing a desire to live with one parent over the other.



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Joe: So that case is purely about that. I think we all felt that she was capable of making that decision. So that was about that. So maybe a limited decision making in that particular instance was okay. But in other another sense, there's a spectrum of decision making along the line. So, in my mind, process is better than functional decision making. Limited decision making, maybe we go through this process. And if we go through this process and arrive at a decision, then that's limited decision making.

Supported decision making is the process that I would recommend that you go through. And again, on an academic level, there are like ten different steps. You identify the decision that needs to be made. You talk to the person about the fact that they need to make a decision. You determine how do they like to make decisions. There are multiple steps of a decision.

Now, a lot of that can be done informally or formally. It's a process where you work with the person to go through the decision making. Liz's daughter does that. She identifies the decision. She identifies the people that she wants to help her make that decision. And then she comes to the decision. She may not go through all ten steps of the decision making process, but she gets there. We all do that. Or we should be doing that. Not only do all 18 year olds make bad decisions, all 70 year olds make bad decisions, and everybody else in between. So nobody always makes good decisions.

People who don't have disabilities don't have guardians are not imposed on when they make bad decisions. So, there's got to be some leeway here. When you go through this process, one of the problems we have with some of the models of supported decision making laws is that the court will write an order saying that so and so has – let me back up one second. The important distinction between supported decision making and a guardian is the legal decision maker is the individual in supported decision making. In guardianship, the legal decision maker is the guardian.

Ellen: Okay, so that's a very important distinction.'

Joe: Right. And there are all kinds of good reasons for that, and you can back up and do other things. You can have a power of attorney and a variety of other things in between. In some states they will write an order saying we're having a supported decision maker. So



and so is allowed to make decisions and this is the person who will assist her in making the decisions. Well, again, as Liz and you indicated, we don't do that either, right? We don't go to the same person for every decision we want to make. That's right. A good, supported decision making thing should be a process where the person is allowed to identify who's going to help the person make that particular decision.

But again, courts are not comfortable with that because they like to assign responsibility at some point to somebody to say they're the ultimate person responsible. I think there are only three or four jurisdictions where there are actually supported decision making laws. There are a couple more jurisdictions which have allowed supported decision making as part of a guardianship case. But again, they have some limitations that I would like to see expanded a little bit more.

Nina: On that note, which is very odd because I would love to hear from Joe, I want to get educated here about supported decision making. In the form Report of Counsel in New Jersey, it lists ten items asking what less restrictive things did you consider? And then why are they not appropriate? And supportive decision making is on there. I always look at that and I think, what if I checked off supportive decision making, what would the court do in New Jersey? Because I believe that that is a checkoff box on the report.

Ellen: Yes, there is no statute in New Jersey.

Joe: There is no statute. And although that wouldn't prohibit a court from making a court order, I have never seen one in New Jersey.

Nina: So, in many of these cases, I always say just because you have disabilities doesn't mean you need a guardian. And that's these cases where I get appointed. The medicals say this, I understand this, they have down syndrome. They have autism. Yes. It doesn't mean they need a guardian. I think the courts and the parents miss that need component because, like the case I was recently appointed on, he was already 21. They procrastinated filing. They had other family emergencies, so they got backlogged in filing. I said, "he's been without a guardian for three years. He actually doesn't need it." He may have disabilities, but you function without it, probably through some informal supportive decision making mechanism. You know, they get the reports and they file the guardianship and there's only so much Court Appointed Counsel can do once it's filed.



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Joe: If the individual is living in the community, is verbal and ambulatory, they're making their own decisions. I mean, they can have a guardian, but they on a day to day basis are making their own decisions.

Ellen: Liz, are there fears that you had as a parent that made you think initially, oh I should get guardianship?

Liz: Yes, well again, it was going back many years and there really wasn't much talk about anything but having guardianship if you had a child that had the label, you became the guardian. The biggest fear that I have with people who are able to make decisions, but maybe don't have the verbal ability to convey that, is in the medical field. That's maybe because I'm a nurse, too. My concern is somebody is in the pre-op, and the anesthesiologist comes in and says, I can't accept informed consent.

Years ago, I was a nurse for an agency that did group homes. Years ago, doctors let them get away with murder. I mean, there's no way this person could sign anything, and they would say it was okay. And that pendulum has swung, where doctors now are very hesitant to allow someone who they don't think has the competency to sign something. And then we're stuck with, okay, now what do we do? The person doesn't have a guardian and they need this medical procedure. That's the only thing that scares me with a lot of folks with cognitive issues.

Joe: Right, that's where we do protective lawyering, right? That's where I would recommend that in the mental health field, particularly, this is a problem, where somebody gets into some psych hospital, and they have to start arguing with people about whether or not they're allowed to refuse medication and stuff like that.

That's where my suggestion would be you get a power of attorney. You talk to the individual about the role and say, I know that you're capable of making decisions. We're going to work together to make sure that whatever you want is going to be agreed to. But there are people out there who are going to cause problems. So in order to protect you to make sure that you get what you want, we're going to do a power of attorney so that if there's ever a problem and they say that you can't have what you want, they'll come to me. Because I'm your power of attorney and I will be your advocate in that situation.



## TOGETHER WEPLAN EP. 3

### Beyond Guardianship: Exploring Supported Decision Making

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And that's good lawyering in my mind. So, first of all, my classic joke is that they don't start asking you to sign consent forms until they administer the anesthesia. (laughter). So, if you run into that situation where a doctor says you can't do that, or they won't do this, or you can't refuse medication or whatever else it may be, there's another person there on a document who's going to be your advocate in that situation.

Liz: Joe, one of the things I've always wondered about power of attorney: if a person is on the borderline of needing a guardian, will a lawyer allow them to write a power of attorney?

Joe: Yes, it's the consent thing. There are different levels of consent. In my mind, the person who's signing the document doesn't have to understand every item that's in the document. They just have to understand that in the event that they're not able to make decisions or somebody won't allow them to make decisions, this is the person that they want to make that decision.

Nina: What I do in my practice, because I've handled a few restorations to capacity, is once you restore them, you don't want to leave them with nothing. So, we'll do a power of attorney and a Healthcare Proxy. And in a situation like that, I would simplify my documents. Some advanced directives give each medical scenario. If I'm in this situation, someone with diminished capacity might not have insight, but they know who they trust, and they know who they want them to make decisions. So, I would simplify my document where they sign what's called a proxy directive.

Basically, if I can't make my own medical decisions, I want my mother. But they're not delineating every single thing that they could certainly understand. I know my mother. I trust my mother. They can sign a simplified version of it. That's normally what I do.

Joe: And so just as an aside, whenever I do discussions about proxy directives and things like that, I'll let everybody know that in the event that I'm in some kind of dire situation, my wife is not allowed to pull the plug. She can make any other kind of decision, but she's not allowed to pull the plug. So now I have lots of witnesses around the state. (laughter)

But the other financial thing is the joint bank account. It's exactly the same thing. The person has a bank account. You're named on the bank account in case you need to be there, but the person gets to make the decisions. We all do that at some stage, right? We all do that





for our parents. So that's another simple way of not having to go through all these procedures to accomplish your goal.

Liz: That's a great response. My husband and I have power of attorneys and healthcare proxies, and we've discussed with my daughter, what if she was very sick? What would she want? We have those discussions.

Nina: I was going to ask you if your daughter had those documents.

Liz: Yes, she doesn't. It's something that we will have to attend to, and it's interesting. We have very competent lawyers, and no one has suggested that.

Nina: That's surprising.

Liz: I mean, they have the special needs trust. We have all our documents up the wazoo, but nobody ever said that about her. And frankly, we said, well, she's not old, you know.

Joe: That's it. Everybody thinks until you're 50 or 60, you don't need that, but that's not true.

Nina: You could step off the curb and get hit by a bus.

Liz: Exactly. People have said the doctor would always defer to you if she was unconscious or something because you're the next of kin, but it is a handy document to have.

Ellen: So, this is really fascinating. Before we end, let's just talk briefly about conservatorship. We don't see that much in New Jersey. PLAN|NJ has been asked to be conservator in a couple of cases. Would one of you like to explain what that is, Nina?

Nina: I've done them. You're right, I call it an underutilized tool. I use it more in the elder population. I don't know if I've ever used it in the young adult population. I refer to it as like a court sanctioned power of attorney. Unlike guardianship, conservatorship is a voluntary arrangement. A guardianship is an involuntary arrangement where a court imposes it on someone, not necessarily against their will, but they don't consent. Whereas a



conservatorship, the person has to have capacity, and they either have to ask for it themselves of the court, or someone else might ask for it on their behalf.

Let's say you have an individual where you think they're competent to do a power of attorney. They're living in the community, it could be a young adult also, and maybe they're unusually susceptible to exploitation. Maybe they have roommates or maybe they've signed contracts for fancy cars, you know, whereas a power of attorney might be not enough protection.

Because like a power of attorney, you can revoke it at any time. It's a voluntary arrangement. You can give a power of attorney to someone; the next day, you can say, "I hate you and leave me alone," then it's effectively revoked. So, conservatorship gives an extra layer of protection in the financial arena, whereas if you think someone can be susceptible to competing powers of attorney or to revoke it, the court can impose a conservatorship. It's only over financial affairs.

Ellen: Okay, it's not about personal decision making.

Nina: It's basically a court sanctioned power of attorney, and the reason why it's more protective is that in order for a person to undo it, they have to return to court. But the court has to be convinced the person is consenting. Sometimes I've used it if someone files for guardianship over property, sometimes it could be used to settle a matter if you think the person does have capacity, but they do need someone to help with their financial affairs. And not everyone can ask, you have to have some kind of impairment to seek a conservatorship.

Joe: Is there also some kind of protection for the individual in that the court oversees the administration of the conservatorship?

Nina: You mean like whether there's accountings? I don't recall what the statute says, but most likely. So, it's like a next level; it's a court sanctioned power of attorney.

Joe: And Nina mentioned another one of these bizarre things, the Catch 22s that happen in New Jersey. Occasionally you'll see something where a court says the individual consents to the guardianship. Well, if a person is consenting to the guardianship, they don't need a guardian. So it's one of those bizarre things that somehow every once in a while happens in Jersey.



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Ellen: We seem to have a lot of bizarre things that happen in New Jersey.

Liz: But we're in a fun state.

Nina: That's right. So, a conservatorship might be handy if, let's say someone has signed a power of attorney but perhaps a bank questions their capacity to have signed the power of attorney. Would you say that's the case?

Nina: That could be... but if that's the case, then do they even have capacity to do a conservatorship? But you're right, a bank would certainly honor a court order more than just a document. But again, I've used it more where there's more potential risk and you just might need that extra layer of a court order, if they're in the community.

Joe: My first question is, if a person with a disability has that much money that we're going to talk about a conservatorship, maybe we ought to be talking about some other financial planning at the same time.

Liz: is it different than a trustee?

Joe: Yes. That's where we get really arcane and confusing because again. A parent or the individual can select the trustee, and then the trustee is supposed to make decisions for the individual, but it's a whole different kind of document. It's not overseen by the court. The trustee is appointed by the individuals themselves. The conservator is appointed by the court.

Nina: It could also be a very useful tool in the mental health field. where capacity is transient. So depending on if someone's compliant with their medication or not, those are very difficult guardianship matters. But a conservatorship, where there's a court order, maybe there's someone with mental health issues and they're having a diminished capacity, maybe an advanced directive for mental health coupled with a conservatorship could be like the least restrictive way to deal with transient capacity issues. It's not utilized much, but it is a good tool.

Joe: I had a client that inherited some money; \$70,000. He had a mental illness, had no guardian at all until he inherited some money. All of a sudden the family says he needs a



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guardian. So, we tried to say, no, he doesn't need a guardian. In fact, he doesn't even want the money. You can take the money, leave him alone. The court appointed a guardian anyway. Again, this is 30 years ago. So much less enlightened times. And I was a new attorney, otherwise it would have done even worse.

And that was a hearing that was held over the phone. I asked the psychiatrist, "Are you administering medication?" The psychiatrist said, "yes." "Are you allowing the client to consent to the medication?" The psychiatrist said, "yes," and the judge still appointed a guardian. So, the case made no sense. Conservatorship or even limited power, a guardian of the estate, would have been appropriate in those situations.

Ellen: Well, that is one of the misunderstandings about guardianship. Sometimes people assume, well, if I'm a guardian, I can force this person to take medication, when that is not the case. The person still has the ability to choose whether to take medication or not.

Nina: And you can't commit them, either. You can facilitate voluntary admission, but if they refuse, they have to meet the commitment standard.

Ellen: Yes. Well, does anybody have anything that you want to add to this conversation? It's been fascinating and enlightening.

Joe: Yes, education should be focused on supported decision making. It's something that we all do in our lives. It's a natural thing. It's not an unusual thing. Everybody talks to different people to help them make the decisions. My mother, when she was older, said she didn't want to go to the doctor. And I said, no, you're going to the doctor. I didn't get guardianship to make her go to the doctor. She wanted me to make decisions so she could yell at me when she didn't want to go. But we all do that kind of thing. So, it's a natural thing, to go to others, help us make the decisions. We are not all competent in every single sphere.

Nina: Where is New Jersey in that?

Joe: So, my understanding is that in fact the Bogg's Center UAP, and I think the Developmental Disabilities Council are involved in an effort to get a grant as a pilot project about supported decision making.



Ellen: Correct. And Disability Rights New Jersey.

Joe: The grant is to do some things in one county, in developing some supported decision making projects and programs, but it's going to take a long time. Most courts, most states are still very reluctant. A plug for their website: [Supporteddecisionmaking.org](http://Supporteddecisionmaking.org) is the national website for supported decision making.

Nina: The problem I see, and maybe this can be a paradigm shift. I think the attorneys who represent families - and the families - don't see any harm in what they're doing. I think that's the paradigm they're filing under. They don't see any harm and there is inherent harm, but they don't see it that way. And that's the battle. It's terrible that it has to be a battle, but that's where a court appointed attorney comes in. It's difficult because that's the paradigm that they're operating under.

Joe: I think there's a simple solution in New Jersey because 90 percent of it is already in the statute. You have to confer, you have to involve the individual, you have to do the substituted judgment thing. So, then all you have to add to the statute is, if you're confident that the individual is making this decision after this process, they are then the legal decision maker. If you're concerned that they can't make this decision, then the guardian - or the person who's there as backup guardian - then they get to be the legal decision maker. We don't even have to change the statute that much, but we do have to change the thinking.

Liz: And I go back to that we really do have to educate the parents and when the kids are little, because the parents need to start having these conversations with particularly the people who have some cognitive intellectual disabilities but are on a track to be that gray area.

Nina: But I often tell the parents, because so many of these parents like you, through 18 years they're advocating in school, advocating, advocating, advocating, they want certain things in their IEP. And then boom, they turn 18, they're going to take it all away, legally, maybe not functionally but legally. I said, this is what you've been advocating for, for 18 years, so that they can go out and work and do this and do that.

Liz: It's a very difficult transition. It's very difficult because it's like sending your kid to college, all of a sudden I'm losing all this power and they're going to have to wade in.



Joe: Well, it's even worse in the school system because the kid says they don't want you in the room anymore. You get kicked out of the room. And that's all goofy. But the important thing is if you educate the families and they start going to the attorneys and say, this is what I want, the attorneys will start figuring out what they need to do.

Nina: Yes, yes, yes.

Ellen: There you go. Well, thank you so much. This was a really fascinating conversation, and we greatly appreciate your joining us.

Liz: Thank you for the free legal advice. (laughter)