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Special Needs Spotlight Webinar Series: Guardianship and Supported Decision-Making

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Guardianship and Supported Decision-Making

Nichole Cipriani: Good morning. This is Nichole Cipriani and Elizabeth McKenna, and we're talking about guardianship and supported decision making today. We're going to start off talking about Guardianships. When your child reaches age 18, that child becomes emancipated or becomes an adult and starts to have certain legal authorities.

So, just as you, as parents, maybe you're the natural guardian for your child while the child's a minor and you make decisions for the child about health care, school, and other legal decisions. When your child reaches age 18, he or she becomes available to make that decision, and in the context of a child with some special needs. Guardianship is appropriate so that the parents can continue making those decisions. So, the New Jersey courts, the laws, and the courts govern Guardianships. So, just prior to a child reaching age 18, if it's expected that your child would need a guardian, and this is a decision that you make with your doctors and with your lawyer, and other advisors, sometimes from the school. The Guardianship is thought—I generally talk to people while the child is 17 so that we can initiate and have a court date around the 18th birthday. So, a guardian is defined in the slide. It's a person who by court appointment has the authority to make decisions for an incapacitated person. And an incapacitated person is an adult who might be impaired by mental illness or deficiency physical illness, or disability, chronic use of drugs, alcoholism or developmental disability, or another cause. But the key is really whether the person can govern him or herself and manage his or her affairs. So, if it's expected that the child will need help with these things, then we would seek guardianship. And it's a careful decision. Now, it's not, it's not just willy-nilly. We do case by case basis. New Jersey courts now have adopted the view that we should have the least restrictive arrangement so that we're not taking away people's rights who are able to take care of certain decisions. For example, if, you know, should we should someone be able to vote? Should someone be able to drive? Should someone be able to be married? I mean, those are things that a guardian would have control over unless they're carved out. So, these are decisions that have to be made, you know, as the child reaches 18.

Okay, we'll talk about the guardian's role. Okay, I think we covered most of this, but I just wanted to talk about us initiating the guardianship. So, we meet with the family and talk about how we want to proceed. Whether it should be a guardianship over the person and property or just the guardianship over one, the person or the property. So, some people are able to manage their financial affairs and some 18-year-olds cannot manage their personal decisions like health care and living arrangements. And they need help with finances. So, the guardian can control assets, manage budgets, pay bills, etc., and also make the personal and medical care decisions where someone lives. If there's continued school education, transportation, all those things. A guardian is a fiduciary. So, you're held to a high role. And of course, not only what is the parent, you're going to act in your child's best interest.

Okay, so when we initiate a guardianship, the first thing that happens is the—I don't want to say child—but the 18-year-old or soon to be 18-year-old is examined by two doctors. And in New Jersey, that first doctor exam triggers a 30-day window within which the complaint has to be filed with the court. And people are afraid of courts. You know, we have clients coming in what is this process about? But most of the courts that we deal with, most counties, it's kind of like a fiefdom, a county by county system, are lovely. And the judges actually will tell you that they wish there was a different process for families with special needs children because obviously these parents are acting in their child's best interest and they really have taken on a higher parental role than a parent of a typical child. So, the first doctor exam triggers that 30-day window which can be relaxed, because as we know, sometimes it's hard to get in with doctors especially nowadays, it can be very difficult. So, what we try to do though, is schedule those in advance, and then the doctors complete certifications, detailing the child's condition, whether the child is expected to improve, and whether the child can be able to manage him or herself at some point. The courts like to see quite a bit of detail. So as much as you're comfortable with. So, the doctors even—some doctors even will attach details—Sorry, I've tried to turn my phone off. So, nobody is calling—will attach a detailed report, which the courts like to see. And if your child has an IEP that's in place, then the court likes to see that as well, as the details from the doctor's report form the basis for the verified complaint.

So, the complaint really is asking for the parents' appointment as guardian. So, it will detail the child's health history and condition and prognosis, and also it will recount what the doctors have said. Okay, and that gets filed with an order for a hearing. And at that point, when the documents are submitted to the surrogate's court, an independent attorney is appointed to represent the child and interview the child, and interview the parents and siblings, and anyone else who has to be served. And also look at the doctor's report. Some attorneys even go so far as to talk to the doctors, if there's any question about the condition or if the child is challenging the guardianship. And then that report is filed with the court. And depending on what county you're in, you have a court date and sometimes it's two months. If you're in a county like Essex, it could be 6, 7, 8 months later, and the judges do like to see everyone now. So, unless the alleged incapacitated person has a condition that would prohibit him or her from coming to court, the judge will have all parties come into chambers, I mean, not to chambers, into the courtroom, and it is a closed hearing. And we will recount what was filed in the complaint. Questions will be asked of the people seeking guardianship to make sure that they will act in the best interest of the alleged incapacitated person. And then the judge normally makes a ruling that day if it's not contested. So, that is generally the process. Again, some of the surrogate's courts, they are very wonderful. This is a process that a lot of families with children have to go through, and the surrogates and the judges recognize that it's difficult. Nobody wants to air all their medical history in the court system, but this is what New Jersey law requires at this time. And so, they'll, you know, facilitate it as gently as possible, I should say. And then, after the hearing sometimes the surrogate even has everything all teed up so that you can sign your qualification papers right there, and qualify as Guardian that day.

So that is—that's generally the process.

And then once your guardian, there are certain requirements, like filing an inventory within 90 days of the incapacitated person's assets, filing an annual report of the well-being. And these are things that—they're not too difficult, they're just kind of a pain, but you know, when you're taking on guardianship of an adult you have to do these things. If the child or the incapacitated—new adult, I guess I should say—the incapacitated person has assets, sometimes an accounting, an easy accounting or a more comprehensive accounting has to be filed each year to make sure that the person serving as guardian is doing the right thing for the incapacitated person and with his or her assets—you know, accounting for all the income, all the disbursements and, you know, if there are other assets, just what has happened with them.

Some people have read horror stories. There was an article a couple of years ago, the New Yorker, about guardianships in Nevada. There are professional guardians, who will take control of people's lives and sell all their assets and take commissions, and while we don't see that happening in New Jersey, their courts do have oversight here. So that's why we have to do these things like the annual report of the well-being, the annual report of the guardian. But, when it's in a parental-child context, it's generally the courts will make it as easy as possible by having easy accounting, and the well-being is really just making sure that the doctor has seen the incapacitated person and that you've been visiting with that person and that their life is going well, that they're having some of the joys of life that they should have. So, that's, that's generally the process. And, you know, we can get into some other things, but one interesting thing arises when guardians are older. Sometimes older parents or older. Older parents of an incapacitated young adult, 18-year-old, or 19-year-olds. And in some cases, we bring in a sibling. So, that if one parent's ill or just really getting on in years, there's a seamless transition to the sibling being Guardian. So, those are some things to consider.

But that is generally the guardianship process. It is not painful if nobody objects, it can be nice. It's fairly cooperative and I usually, if I have a family and it's, you know, the siblings are on board or the siblings are minors and they're not going to object, they usually ask for, you know, I explained that to the surrogate when we file all the papers, so that some, the attorney who is appointed will be kind and gentle with the situation. They do charge, so that attorney does charge, and since the families are paying our fees already, we've asked for someone who is more cost effective if the surrogate is able to do that, so that the family is not charged excessively by, you know, by someone who we might not need that. Someone so, who's been around so long, right? So, we ask for someone maybe who's newer and can handle the situation appropriately and cost-effectively for the family. So, it's, I know it'd be nice to have a more streamlined process for developmentally disabled young adults rising up to 18 at some point, but for now, I think that it's going pretty well. I do just, with a caveat, that if you live in certain counties, when your child's 17, it would be good to contact your attorney to find out when you should initiate the process.

Here in Somerset County where we practice, they will let us file the paperwork while the child is 17 and then the court date assigned is on or around the child's 18th birthday, so that it can be put into place as the child turns 18. That may not be true in other counties. I know Essex County does allow that too, and it takes quite a while to get a court date there. So, it just depends on, and of course, we're living in strange times too. So, things are taking a little bit longer with the courts.

So, I'm going to transition to Beth. But we'll take questions at the end if there's anybody so it looks like there's somebody logged on, but I would just say that you know, not everyone needs a guardianship. So just because you may have a child who has a developmental disability or special needs doesn't mean that you have to have a guardianship. Some people do come to and they think, "Oh, my child's turning 18. I definitely need a guardian." That is not always the case, if your child has the capacity to sign certain documents, like a power of attorney and healthcare directive, and that would be contractual capacity. We can talk about that later. Supported decision making would be a better way to go so that you don't avail yourself of the court system unnecessarily. So, with that, I'll transition to Beth.

Beth McKenna: Thank you, Nicole. And I just wanted to, before I start, just reach back to something you said, which was, and you just went over it again, that the courts are actually also advocating for the least restrictive methods to issues regarding guardianship, and absolutely supported decision making dovetails right in with that.

So, what is supported decision making? It's based on the concept of person-centered and person-driven planning. It began in the 1970s. I've mentioned this at length in previous webinars. It's really focused on giving the person with disabilities more control over the decision-making process. Its people making decisions with advice, guidance, and assistance from trusted advisors. And it's meant to enhance advocacy of the person with disabilities. It's really a model of a process, a system, and a way of life. And it is going to look different for every individual who engages in this process, and their loved ones.

So, to a certain extent, we all do this right? We all have a team around us, be it our doctors, our lawyers, our accountants, financial advisors, and trade people who care for our homes, just the list of few. I certainly know that I couldn't do without my doctor, my plumber, giving me advice on whatever I need to do. Ultimately, the choice in all these cases is ours. But most of us carefully consider their advice before making a decision.

So, how is it defined? This is the recognized definition by Blank and Martinez in 2015. Supported decision making is a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so that they may make their own decisions without the need for a guardian.

So, how does supported decision making work? It really ends up being a balancing point between leaving the person totally on their own, and taking full control of the person's life, as in a full guardianship. So, the person gathers a trusted circle of advisers, and a supportive circle of loved ones to support and empower them when making decisions. The advisors are tasks with explaining facts and issues, offering advice, making recommendations, and guiding choices. And all that activity is always in consultation with the person with disabilities, and always honoring the choices of that person.

The underlying assumptions are, everyone has a right to make choices regarding their life. Of course we do, right? Everyone has the ability to make choices to the extent that they can communicate. And with enough support, everyone can actively participate in life decisions, although there certainly are limitations. For example, the safety of the individual has to be kept paramount. Overall, the choices of the individual should always be honored. It's basically a focus on human and constitutional rights to make choices about one's life. The goal of supported decision making is to protect the rights of every adult and retain and restore the human dignity that comes with choice.

So, what are the benefits of supported decision making with people with lifelong disabilities? Amazingly enough, it is actually extremely good for our children, our young adults with disabilities, to be able to be in this process. It's been noted that they're stable or even improving cognition for persons with disabilities. The research shows that the more people are involved in making decisions, the better they are at making decisions. Kind of make sense.

So, how can SDM help persons with disabilities? First of all, it encourages advanced planning, which I'm always for, being a planner. So, it advocates for the creation of a team to assist the person with disabilities. So, the agents that are chosen have to be trained on advanced planning. They need to be shown how to approach the process by using supported decision-making principles. For example, a starting point might be to sort the choices or decisions into three categories: routine, important, and critical. So, the person with disabilities could be given more leeway on the routine type of decisions. For example, what to wear. And there might actually be less leeway and critical decisions on such as where to live. The legal advanced planning empowers the agents to act and that makes sense, because when a plan is in place, as in any planning situation, the actors ideally know their roles and how to move the process forward.

So, how can supported decision making change the relationship between the person with disabilities and those who help and advise them? It really gives the person a feeling of empowerment. We must always, always, always remember to keep that person at the center of the process. Always involve them, respect their wishes. And it's really not easy. Supported decision making really takes time, patience, and work. That's why choosing the correct team makers who buy into the process is so important. And finally, supported decision making simply just honors and protects the human and constitutional rights of the person, as I already mentioned.

So, how do we begin? So perhaps if we want to consider supported decision making, first we need to maybe presume the guardianship's not needed. We might consider less restrictive options, which Nicole already went over a number of them, including a financial or healthcare power of attorney. So, let's, for example, say Johnny, age 23, who has autism, can handle a job, social issues, and other issues in his life, but he just can't handle money. In this case, a financial power of attorney might be all that's needed. You might also consider a healthcare power of attorney, an advanced directive, a trust to protect the funds of the person, and then, of course, the overarching supported decision-making process.

So next, we want to clearly identify the reasons for concern. So, we just talked about Johnny with his money management concerns.

Health care: Maybe the person doesn't or will not take care of their own healthcare needs unless there is more direct intervention involved.

Relationships: can the person get taken advantage of by people who he or she considers friends?

Community living: Is that going to be a possibility for this person, or is living with the parents or other loved ones going to be the way to go?

Personal decision-making: Is the person making good decisions on a regular basis?

Employment: Can the person stay employed? Does the person know how to, you know, engage in the employment process?

And finally, personal safety: Does the person recognize dangerous situations, or do they have a problem with impulse control that causes issues along these lines?

So, we may ask if a triggering concern may be caused by temporary or reversible conditions. So sometimes, there can be problems caused by grief, perhaps there's been a death of a loved one, the person is in a state of depression. So it's only going to be temporary. Could be a medical condition that's considered, once there is a medical intervention, that the situation will decrease. Sensory deficits, hearing or vision loss are certain areas that can cause issues but can be improved.

Side effects of medication: Maybe sometimes medication takes a while to be regulated properly. So, in that time period, do we have an issue that we have to deal with?

And finally, stereotypes or cultural barriers: Are these problems that we need to be aware of?

So, we need to then determine if the concerns can be addressed by connecting the individual to family or community resources and making accommodations for them. We need to ask what would it take to enable the person to make the needed decisions, or address the presenting concern? What supports would the person need?

Sometimes people already have a team around them, and that is the best thing. If a person has had a lifelong disability, they probably already have. Certainly, their family members, their parents, their siblings are engaged, probably have many, many loved ones who are a part of their circle of support. They probably also have, very likely, attorneys who have been involved in drafting documents beforehand and are engaged in the family in the planning process for the person with disabilities. They might have a financial advisor; they might have an accountant who is working on their team. So, we want to make sure that we are taking into consideration if there is a team, or at least a partial team, already in place. And has the person already appointed a surrogate to help make those decisions?

Then we want to identify the areas of strength because all of all people have them. People with disabilities have strengths and weaknesses just like everyone else. Can the individual make decisions and explain the reasoning in making those decisions? Can the person maintain consistent decisions and primary values over time? Can they remember how they decided something and why? And understanding the consequences of decisions of, you know, rather than as I mentioned earlier, poor impulse control and not seeing the consequences of decisions. So, all of this has to be—if these are areas of strength, absolutely, if there are areas of weakness, that has to be noted as well.

So, then, challenges: We want to screen for and address any potential challenges presented by the identified supports and supporter groups. And here's where we want to appoint a legal supporter or a surrogate who is really in line with the person's values and preferences, is buying into the supported decision-making process. We want to place limits on any necessary guardianship petition in order. For example, as I did for my own son, we have certain carveouts in his guardianship—in his full guardianship, that gives him decision making ability over certain aspects of his life. And those should be taken into consideration for anyone. And again, we need to remember to keep the person with disabilities always at the center of the process to the extent that they can communicate and be engaged.

So, these are some concerns. So, not, you know, not everybody's on board with this as the way to go— guardianship versus supported decision making. You're going to hear people voicing concerns. Perhaps people in your own circle of loved ones. First of all, you know, how do we prevent abuse and exploitation? How do we guide choices when she's making choices not in her best interest? These questions, the person asked the same questions over and over. How can that be that they're understanding what's going on? They forget the choice that they made the other day.

And communication factors: How can we communicate effectively with the person? And there's always a possibility that sooner or later supported decision making won't work. But just because this may be the case, doesn't mean it shouldn't be tried. Planning itself is a dynamic process and supported decision making is no different. I feel that it's definitely the best way forward to give the person with disabilities as much control as possible in determining their life.

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