

Podcast Transcript: Planning care for loved ones with special needs



Kim Insley:

I'm Kim Insley. Thanks for joining us for Navigating Life Transitions. A podcast where we bring together advisors, experienced in financial life planning, to talk about ways to navigate life's biggest changes, challenges, opportunities, and decisions. From growing a family to empty nesting. From earning job promotions to planning for retirement. We discuss these pivotal moments that could benefit from the guidance a financial advisory team can provide.

Today, we're talking about special needs planning. How do you handle financial planning when your family has someone with special needs? Specifically, how do you navigate your situation strategically and with grace toward your loved one? There are several methods to foster constructive and productive planning, and you don't have to do it alone. Joining me is Stuart Bear, an attorney at Chestnut Cambronne. And Elise Huston, an Advisor at JNBA, which serves clients in Minnesota, Florida, and throughout the U.S. JNBA has helped people prepare for and navigate this transition.

I want to say hello to you both.

Elise Huston:

Hello.

Stuart Bear:

Hello.

Kim Insley:

Thank you for being here.

Elise Huston:

Yes, thank you.

Stuart Bear:

Thank you.

Kim Insley:

Elise, I'm going to start with you.

Elise Huston:

Okay.

Kim Insley:

At JNBA, you specialize in financial planning. Shed some light on what it is like for you to deal with clients who have a special needs person within the family.

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Elise Huston:

Yeah. Thanks, Kim. Special needs planning really is multi-faceted. Usually, this originates with a family member of a loved one coming to us wanting to better ensure that the individual with special needs receives the care that they require through their lifetime, but also the financial support to maintain that quality of life. A lot of times, the concerns really are often times about that future care. That can weigh heavily on the family too, if there's concern about how long they themselves may be able to provide care. But then also, that long-term financial stability without compromising other benefits that the special needs individual may be eligible for.

It's interesting. I was looking at a study recently that really surveyed families who do have a child with special needs. Of those families surveyed, 69% of them said that they were really concerned about being able to provide lifetime care for that child. Then 88% of them also said that they hadn't set up a trust for the child to make sure that the financial plan was in place to preserve eligibility for benefits, such as Medicaid or supplemental social security income for that child's future.

Really, by engaging in open communication, seeking support networks, exploring legal and financial planning advice, families can navigate that caregiving journey with often times more confidence. They just have more information. They know the resources; they have that support network in place to really ensure the wellbeing of their loved one with disability for their lifetime. That's really what we do at JNBA. Our job is to pull together a team of professionals and really help that family think through those strategies to figure out what is the best plan for their loved one for their lifetime.

Kim Insley:

As you were talking about that, I think we stress enough about planning for retirement. But you're planning for retirement, and then another 40, 50 years maybe.

Elise Huston:

Yes.

Kim Insley:

Or more.

Elise Huston:

Yes. Yeah.

Kim Insley:

It's hard. It's really complicated.

Elise Huston:

Yes.

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Kim Insley:

Stuart, you're our legal expert today. You specialize in this. I'm just going to say that outright, given the number of clients that you have in this situation. What are some of the key legal aspects that you go over with your clients in terms of special needs planning?

Stuart Bear:

Right. Well, thank you. I think I first want to start with the person with the special needs. I want to play What If. As you were mentioning, we're planning not just when a person passes away, but for the next 40, 50, 60 years. I want to make sure that there's the right legal documents in place that will replicate the authority the caregiver has to assist the person with the disability. I will inquire about guardianship. Is a guardian appointed at this point? Does it need to be appointed in the future? Who would be the contingent guardian? A guardian is the person who oversees the welfare of the person with the disability.

The conservatorship relates to the financial matters. Who's going to assist that person in paying bills or overseeing any assets? Or protect them, so they're not being taken advantage of by another person.

Elise Huston:

Right.

Stuart Bear:

Perhaps, the person with the disability has a bit more capabilities, which is wonderful. Then I want to talk about a financial power of attorney for that person, appointing someone to assist them if they do need assistance with financial matters. That can be, of course, at any point in time when a person needs to step in and assist a person with a disability.

Then finally, a healthcare directive document. A healthcare directive document is critically important because, first and foremost, it has a HIPAA release in it. The advocate then can know what's going on, from a medical perspective, and really provide that person with the disability assistance. It also goes on to talk about end-of-life care. It talks about who would be making those decisions, those substituted decisions, if the person with the disability is not capable of making the decisions. Then it goes on to some other things that I think are rather empowering for the person with the disability. Whether the person with the disability would want to be an organ and tissue donor when they pass away. And also, what's to happen with their remains. Do they want burial or cremation? If it is a burial, where to be buried. And cremation, where they want their ashes scattered.

Kim Insley:

The timeline of this is so difficult because you may designate all of these people who may not live long enough for that person's life. You may be talking about a 10-year-old child who's going to be having a different opinion maybe about end of life things when they're 25 and an adult. I would think you would have to revisit this plan fairly frequently.

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Stuart Bear:

Yes. Even though I draft into the plan that the named representatives typically have the ability to name their successors to provide continuity, or name a list of potential people who could be the successors, I try to instill in my clients that really, the true shelf-life of any good plan, from the legal perspective, is three to five years.

Now that's not to say we throw it away. But the moving part with anything is human beings that come in, in our lives. I think when we think about what our friendship circle looked like, say five years ago, and then 10 years.

Elise Huston:

True.

Stuart Bear:

It's just different, and that doesn't mean it's wrong. But this gives us then the power, the authority to address situations as they develop.

Elise Huston:

Well, similarly too, it's really with any estate plan that you revisit. To Stuart's point, the people in your life change, but also the makeup of your family continues to change. To your point, maybe if this child you're planning for is 10 years of age, they may have siblings that are minors as well. As they all mature, and get older, and reach adulthood, you, the parent, may feel differently about maybe having a sibling serve in some of these roles.

Kim Insley:

Right.

Elise Huston:

Or maybe, siblings, by that point, can express that they don't want to have to be the one gatekeeping for their sibling. They want to be there for their sibling in other ways, and they would prefer to have independent professionals or others involved in the plan as well.

Kim Insley:

Yeah, good point.

Stuart Bear:

That's a great, great point. In fact, that's something I do talk to my clients about. That there's roles for the sibling to play, in terms of maybe being the safety net or the overseer. But in terms of being involved with financial matters, and being the one who has to inform their sibling that they can't have an expenditure for this, but they can have an expenditure for that, that really I think interferes with the sibling relationship. Really, I've noticed when the last parent passes away, the

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siblings in any family are negotiating their relationship with each other going forward. To impose a certain hierarchy, one sibling over another, I think can damage that relationship.

Kim Insley:

Yeah, that's a good point. To your point, Elise, a sibling might not want that responsibility.

You, and Elise alluded to this too, all of the programs, and the things, and whatnot. Stuart, there are a lot of tools a family can work with. Can you go into some of those for us?

Stuart Bear:

I shall, yeah. I think the core document for a family with a child with a disability is to consider what we call a supplemental needs trust. A supplemental needs trust is a very special kind of trust created through our statute that allows this to happen. It says that the person with the disability may remain eligible for any governmental benefits, whether it's Federal or state benefits, and become eligible for those benefits as well, without the inherited assets held in the supplemental needs trust jeopardizing their eligibility or continued eligibility.

By supplemental needs trust, I mean the trustee of the trust then, when the trust is funded, typically at the death of a parent or both parents, the trustee then has an understanding of the benefit programs and what they pay and is allowed to pay for assets that supplement those programs. They don't replace benefits, but they supplement it. Which means that it really enhances the quality of life with the person with the disability. Those things that can supplement a person's life include entertainment expenses. Maybe the person enjoys going to the local amusement park, or plays, musicals. Or concerts. Or the trip to Disney World. Those are all important things that would never be covered naturally under a government benefit program but serve to enhance the qualities of a person's life. Maybe that person likes to wear certain accessories. She likes to wear a certain kind of earrings. Or have a certain new purse. Those kinds of things. Or a backpack that's really cool.

Hey, there are some really cool backpacks out there.

Kim Insley:

There are.

Stuart Bear:

Those are just an example of what it does. See how it enhances that person's life? And see how it gives them some dignity?

Kim Insley:

Yes.

Stuart Bear:

That's what it's all about.

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Kim Insley:

It's more than just the basics. There's the supplemental needs trust, and then there's a special needs trust. This is a different thing?

Stuart Bear:

It is a different thing.

Kim Insley:

This is why it's confusing.

Stuart Bear:

I know, I know. Well, that's why we need lawyers. Hello?

Elise Huston:

That's why you're here, Stuart.

Stuart Bear:

Yeah. Let's just talk about this. A supplemental needs trust is from third party money. I'll use this piece of paper as an example, and I'll pretend this is my trust. Now, if it's written by a lawyer, it's going to be this thick. I know. But this is the trust.

Third parties put their monies into this trust, typically at death. That can benefit the person with the disability. I like to establish the trust now, with a pour-over provision from, say it's mom and dad, to have their assets go into this supplemental needs trust when they both pass away. But also, because it's already set up, other family members can benefit the person with the disability without jeopardizing legal benefits.

The special needs trust is different. The special needs trust is called first party money. What's first party money? Well, let's say our person with a disability was fine, they didn't have a disability, but they were involved in a horrible car accident and they became a paraplegic.

Kim Insley:

It's their assets.

Stuart Bear:

It's their assets. The difference between the two is that with a special needs trust, there's what's called a payback provision. The government is saying, "We want the person who was injured in this accident to benefit from the award that they were able to achieve from that accident." But when they pass away, then the government has lien rights against those benefits, both the state and Federal authorities, and they can impose their lien, and seek reimbursement for the benefits they paid over the person's life.

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Kim Insley:

For what's remaining in the special needs trust?

Stuart Bear:

Exactly, exactly. Sometimes a person may well have, if they're the victim of an accident, they may have two types of trusts. They may have a special needs trust with their award that they received from the personal injury action. And then their parents may set up, or other third parties may set up a supplemental needs trust to supplement as well their benefits.

Kim Insley:

Then there's an able account.

Stuart Bear:

Yes.

Kim Insley:

Which you've described to me in the past is think of a 529?

Stuart Bear:

Right. In fact, the code section is 529A. That's the IRS being cute because we know they have just a wild sense of humor. It's called 529A, as in an able account. Able, making a person able to achieve certain life goals.

An able account has more restrictions on it, but it's very easy to set up. You don't need a lawyer to set up an able account. You open it up very much like you would open up a 529 plan, or a Roth IRA. The idea is that the assets continue to grow in this account tax-free. When they're taking out for the benefit of the person with the disability to pay for things that would supplement the beneficiary's life, to enhance the quality of the beneficiary's life, there's no taxes associated with that.

There are certain limitations. One limitation is that the person must be certified as having a disability by age 26. Fortunately, the law is going to change. By January 1st, 2026, so when we think of it, it's just another 18 months away. I know, hard to believe.

Kim Insley:

Right.

Stuart Bear:

Right? If I have my math straight, I think I do. Right. It's going to increase to age 46. How the government comes up with these ages, 26 or 46, I don't know. But I'm glad the government came up with those ages because sometimes a disability doesn't necessarily manifest itself by age 26.

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Elise Huston:

Right.

Stuart Bear:

Or to the extent of that disability. That's a lovely extension to this rule.

Kim Insley:

Can I jump in? If you are the victim of an accident though, does that change that number?

Stuart Bear:

No, it does not. But provided that the accident happened, and the award was received before you're age 46.

Let me explain. Right, right. Age 46 is the cutoff date.

Kim Insley:

Okay.

Stuart Bear:

If a person was in a car accident and they were age 50, and at age 52 they receive an award, they'd be prohibited from putting money into an able account.

Kim Insley:

Okay.

Stuart Bear:

There's still other things available, though. There's the supplemental needs trust.

Kim Insley:

Yeah.

Stuart Bear:

Think of it this way. Lawyers, they have a whole tool belt. Just like a carpenter has a tool belt, there's a hammer, there's a screwdriver, there's a pliers. That's what you're getting when you're speaking with your lawyer. She or he has this whole tool belt. They're going to explain what tools might be best for you. It also might be a combination of tools as well, because it's all about providing for the dignity of the person with the disability.

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Kim Insley:

That's a great way of thinking about that. I like that, Stuart. It again, Elise, brings to mind the complexity of all of this. And misconceptions. In my wildest dreams, I would never think there would be a cutoff age for when you're covered by a disability status or not.

Elise Huston:

Yeah.

Kim Insley:

What do you find when you're helping families, some misconceptions people may have going into this?

Elise Huston:

Yeah. Often times, this may be a change to your family dynamic or a transition that you were not anticipating. There is a long period of discovery often, for these families. But then, comes with that sometimes some misconceptions just because they assume something that may not be true.

One that can be somewhat common is the assumption that the government programs to provide some financial support to these individuals, they alone will suffice. A lot of what Stuart talked about is just these other tools in the tool belt allow you to supplement those programs to expand upon their quality of life. And provide for what maybe others would deem as those extras, but that help to make up that person's passions, interests, and give them a fulfilled life. That can be an often misconception.

Maybe there's also not an understanding on what those gaps in coverage could be. Or maybe too, they just think, "Oh, I can just give my child, or this family member, additional monies on top of their programs with no issue." They're not aware of some of those limitations that might put some of those programs in jeopardy.

Another, I think too, is just the emotional toll. Or around the fear and the worry that family members can often have around this. I'm sure once you're in the midst of it, and you are not advocating for this individual, it's probably become somewhat apparent just how much of a toll that can take on you and your family members. We often times will hear questions saying, "Who's going to care for them when I'm not here? I'm their parent right now. I am committed to the care of this individual. But if I'm not here or I can't, who will?"

Then also, just as I get older myself. If I'm no longer physically able to lift them, if they need to be lifted from a wheelchair into bed. Or if there's different things that require just some physical support for the individual. How are we going to pay for that? Who can help with that? What are my resources? I know there are a lot of wonderful communities and resources out there to help families navigate all these questions and just plan for these concerns.

I know, Stuart, you and your team have quite a thoughtful list of resources and others that you can put families in touch with. As do we, at JNBA. If you are wondering and wanting to explore future housing options, maybe you're curious, is there a group home that my child could live in? Where it still feels like they're living in a house, but they may be with others who have a similar disability or

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lifestyle. But there's 24/7 care, and nursing care there in that home. There are resources. There are people to talk to, to explore your options in that scenario.

But also, just even support groups. Having a community of other families or other individuals who are navigating this same change to their family dynamic, who maybe have similar questions and concerns, to be able to lean on one another can really be helpful as you're trying to wrap your mind around what the future for yourself, but also your family members will look like in the midst of this change.

Stuart Bear:

I think you raised such a good point. Because part of the holistic approach that I know we both take is a focus on the person with the disability, but also on the caregiver. Making sure that they have mental wellness and physical wellness as well. If we can insert, in our planning, opportunities for them to get some respite care, they're going to be just that much better of a caregiver.

Elise Huston:

Right.

Stuart Bear:

I think it starts with what you were saying, making sure that the person with the disability has good places to be. A good place to live, the security of people around them who look out for them. I think that gives the caregiver a lot of peace of mind.

Elise Huston:

Exactly.

Kim Insley:

Yeah. It's not about I have to save every penny that I have so that I can make sure, again, that these funds last another 60 years beyond me. But realizing, in order to provide the best care, maybe you have to spend something now. To me, having the team to help you through this because mistakes can be made, and they can be really costly if you don't know what you're doing.

As we wrap this up, Elise, I'll start with you. What advice do you have with families that are just starting this very long journey?

Elise Huston:

Yeah. I think start early. As Stuart's alluded to here, there's a lot of tools and resources out there for families who are navigating this. It will likely change over time, too. As the individual with the special need or the disability, as they progress, as they maybe do seek out their own programs, maybe they even start to take some classes, maybe they are hoping to become more independent themselves, the planning work that needs to be done for them, the support that needs provided to them will change. Definitely seeking guidance from professionals early can be really helpful, just to make sure that you're taking advantage of not only the resources that are available to you, but

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that there's a clear plan with goals in place that all family members or loved ones can know about to help make sure that we are advocating and setting this person up for that lifelong success.

Kim Insley:

What would you advise people, Stuart?

Stuart Bear:

I would say that the collaboration between the lawyer and the financial advisor is really key to the relationship. I know when working with JNBA advisors that they are very collaborative. I enjoy it because I can make legal recommendations, but so much of it is financial as well.

The example is the supplemental needs trust. It's perfect, it's wonderful from a legal perspective. But now, we have to identify assets to go into that trust when a person passes away. That's where the financial advisor is really, really invaluable to the relationship. Because of that, I think the lawyer and the financial advisor providing this holistic outlook, this holistic approach is really, really good for the benefit of the clients.

Kim Insley:

It's a tough topic. I want to thank you both for helping us. I know, for people who are listening, we're just scratching the surface here. There's so much more to learn. Thank you, Stuart, and Elise. This has been enlightening. Thank those of you who are listening, there's so much more to learn.

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