Together we PLAN - Your Legacy of Love: Estate and Financial Planning for Families with Disabilities

In this episode of the PLAN|NJ podcast, Executive Director Ellen Nalven and Director of Trust Services Nancy Dilliplane speak with elder law attorney Tom Begley, Jr. and associate attorney Emily Schurr about how estate planning can protect loved ones with disabilities and preserve essential public benefits.

PLAN | NJ Podcast Series

Ep. 9: Your Legacy of Love: Estate and Financial Planning for Families with Disabilities

Ellen: My name is Ellen Nalven. I'm the Executive Director of Planned Lifetime Assistance Network of New Jersey, and my co-host for today's podcast is Nancy Dilliplane. Welcome, Nancy.

Nancy: Thank you, Ellen.

Ellen: Nancy is our Director of Trust Services at PLAN New Jersey, and we're so pleased to have Tom Begley, Jr. and Emily Schurr with us today to talk about legal and estate planning for people with disabilities and their families.

So let me introduce them. Tom Begley, Jr. is a lifelong resident of southern New Jersey. He earned both his undergraduate and law degrees at Georgetown University. In a career that spans over 60 years, he has extensive experience in elder law, Medicaid planning, special needs trusts, disability law, and personal injury consulting.

Tom is a certified elder law attorney, a fellow of the National Academy of Elder Law Attorneys, recipient of the NALA President's Award, and a former board member of NALA. He's past president and a founding member of the Special Needs Alliance, a national network of lawyers dedicated to serving the families of persons with disabilities.

Tom is AV rated by Martindale-Hubbell, which is only awarded to lawyers operating at the highest level of professional excellence and upholding the highest ethical standards; and he is recognized as a New Jersey super lawyer. Welcome, Tom.

Tom: Thank you. It's nice to be here. Thank you for inviting us.

Ellen: It's our pleasure. Emily Schurr is an associate attorney at Begley Law Group. Emily's focused areas of law practice include special needs planning, personal injury consulting, and estate planning. Emily received a BA from Rowan University and her Juris Doctorate from Rutgers Law School. She's a member of the Bar Associations of New Jersey, Pennsylvania, Philadelphia, Burlington County, and Camden County.

During her time at Rutgers Law School, she completed over 100 pro bono hours, earning the Dean's Pro Bono Publico Award for Exceptional Service, and the Mary Philbrook Student Public Interest Award. She was a teaching assistant for estates and trusts and estate planning classes, and served as a student leader of the Planning Estates Project, which prepared estate planning documents for low income seniors. Welcome Emily.

Emily: Thank you so much, Ellen. It's a pleasure to be here today.

Ellen: Thank you for being with us. Nancy, would you get our conversation started, please?

Nancy: Emily, Tom, thank you again for joining us. I want to start by talking a little bit about some of the reasons that families come for your guidance.

Tom: Well, it's almost always the same reason. For a family, they usually come because somebody told them they need a special needs trust, and that's the only reason. So that's when we have to explain to them that a special needs trust is only a tool in the toolbox. And they really need to start out by developing a plan so they know what is a good life for their child and how much it's going to cost. And that way they can figure out what they would need to set aside in the trust to be able to fund the good life.

Nancy: Excellent. So what are some of the goals of this type of planning?

Emily: So the goals are to really set a standard for the life that you want your loved one to have after you're gone. The idea is to protect the public benefits and properly fund the trust. And to do that, it's important to create a budget and know how much is needed in order to fund that lifestyle.

Nancy: And are there things this planning is intended to either provide for, or to avoid?

Tom: Well, we would suggest that they get a professional to do the plan, and PLAN New Jersey does do life care plans. So that would be a place to start. And the big things are, who's going to look out for this kid after the parents are gone? I personally have a daughter and grandson with disabilities. As long as I'm here, they're going to be fine. When I'm gone, what's going to happen? So that's what the parents have to start to think about.

The natural inclination is to say, well, my other kids will take care of him, and they'll live in my house, and my daughter will move in, and everything will be wonderful. And then what happens is, the parent dies, and they can't afford to keep the house, and the daughter is married, and her husband says, no way am I moving into this house, or having anything to do with your brother.

So you have to kind of think through all of these things, and maybe you come up with a plan A and a plan B. So if plan A doesn't work out, who's going to take care of the kids? What can they do in the way of work, if anything? And where are they going to live? These are the three big problems that we see, and you probably see a lot more.

Nancy: Absolutely. We certainly do.

Emily: Other things that we see as far as do's and don'ts - it's an important conversation to have - in the estate plan, how much money we should be giving to that person, and whether we leave everything outright to a sibling, whether they are going to take care of their sibling with a disability. A lot of parents think, you know, we will just disinherit the individual with a disability so that they stay eligible for their public benefits.

And that's where the trust comes in and we can make sure that's funded. It protects the benefits and there won't be any problems with the public benefits or the money going to the child as long as it's in that trust. The other thing that sometimes individuals do, they will just leave the money outright to the individual with special needs. And we have the opposite problem there if we give too much money to the individual, then they are going to lose their public benefits after the parent passes away.

So we want to avoid that as well. And then of course (there is) the age old tale of a family member serving as the trustee of that special needs trust, which can be problematic. You know, we hate to ever think of anyone as creating a burden, but we don't want to put unnecessary pressures on a sibling. So a corporate trustee serving as the trustee of a special needs trust is sometimes the best route to go, where the sibling stays involved in their life without it ever becoming a hassle, because that corporate trustee is able to act as a liaison and really provide the other services so that everyone can live a comfortable life.

Tom: When we first started doing these trusts many years ago, people would always come and they wanted a family member to be the trustee and we always said, fine. And then we started to see the trust blow up because the family member didn't really understand what was involved. The public benefits rules are complex and they change all the time.

So maybe the child who's going to be the trustee studies them in the beginning and then they change; they keep operating under the old law, they disqualify the person from their public benefits, and then they get sued because as trustee, they're responsible to follow the rules. And if they don't, they can individually be surcharged.

We were just involved in a case where there was a professional trustee, they got sued, settled a case for $200,000. So if that's your son or daughter, that's coming out of their pocket. Once you explain that possibility to them, they don't want to be the trustee anymore.

Nancy: One of the things that we've noticed also when we meet with families is that when they're doing their estate planning, and they are appointing a family member to serve as a trustee, itt seems to be, in many of the cases, an individual who is around the same age as the parents. So do you see those as well when they come to you, with those ideas of naming my brother or my sister?

Tom: Well, it's mostly their other kids. But the other kids have their own lives, they're busy. They have their own kids in many cases, and they don't really have time to do it. Or the expertise to do it. So we haven't done one with an individual as trustee for many, many years. Because once you explain it to people, they understand it. They don't want to do it.

Ellen: Many families hear that it's important to go to a lawyer and do an estate plan. But they really don't necessarily have any idea of what that means, what they're going to accomplish. Tom, you've mentioned that they might be asking for specific tools, specific legal avenues, but they just don't know necessarily what does that look like? What does that mean? What's going to happen? What would you suggest that they do in order to prepare for that meeting with you? What should they be thinking about? What are the things that you need to know from families as you begin this process?

Tom: Well, we actually send an intake form, and we need to know people's names, addresses, social security numbers, email addresses, telephone numbers, and we need to know what is the disability? What are the diagnoses that this child suffers from? And then we need to know what benefits are they receiving, and frequently we find out that there are many benefits that they could be receiving that they're not. And then we try to find out what their abilities are, what they can't do, and do they need a trust? We try not to do a trust if they don't need one, but usually they do.

The big mistake that people make in this arena is they say, we had this yesterday family came in, terribly disabled son, he had cerebral palsy, or rather he had Down syndrome and autism, both. And they were going to leave all of the money to one of his siblings with the understanding the sibling would take care of the kid with the autism and Down syndrome. Well, we've been down that road before, and when it comes time to get the check for the kid's needs, they say, I have the will. There's nothing in there about me having to use the money for my brother. It's my money, and I have my own needs. He's just going to have to live on his public benefits. So you never want to do that.

Or maybe the sister is willing to spend the money, but the sister's spouse isn't willing to spend the money. We've had cases where they actually set aside money in a separate bank account in the sister's name, husband got laid off, got behind in the mortgage payments, took the money out of the account that was supposed to be used for the brother, but they used it to bring their mortgage payments current. Husband got a new job, didn't make as much money as he got on the old job. Every month they take money out of that account to pay for their own mortgage. Kid doesn't live with them, but, you know, it's not a good idea.

Ellen: So the families have an idea of how they want the child with a disability to live, but if they're not planning properly, their vision may not come to fruition.

Tom: And they love all of their kids equally. They trust them. But when push comes to shove, our experience is it doesn't always work out the way the parents think it was going to. And it's not always the kid, it's often the spouse of the kid.

Emily: We want to plan for the unexpected. Some parents assume that the funds from, say, DDD, for example, are always going to be there. And public benefits change, the rules change, and the resources change.

And so, we want to make sure that everything is properly funded for the unexpected. And that's really what it's all about, making sure that we aren't relying on a family member too much, where their life circumstances can change, or public services and public benefits that can also change as well. So, the proper planning for that, and planning for the unexpected, and thinking about things that are hard to think about, that we don't want to have to acknowledge, but having those difficult conversations are really what set us up for success.

Nancy: We tell families that they need to plan for the worst case scenario. You don't really think about much when everything is going well.

Ellen: So, as you mentioned, public benefits change, the eligibility requirements change; what you feel like you can count on now you may not be able to count on. So what are some of those public benefits?

Tom: We had a case yesterday, and the kid's going to net $3.5 million from a personal injury. This is after all fees, costs, and liens are paid, and he's on SSI and Medicaid. They want a trustee who will not administer a special needs trust because they're wise enough to see the liability on their part.

So, their solution is get the guy off of SSI, get him off Medicaid, and let's get him covered under the Affordable Care Act. So, we already know the Republicans have tried four times to have the Affordable Care Act repealed. So, let's suppose we do this, and then the fifth time, the Affordable Care Act is repealed.

Where's the kid? He's got profound disabilities, very expensive care required. They're spending $2,500 a month just for physical therapy. So if they have that covered, then they're going to be fine. If it's not covered, they're going to run out of money.

Ellen: Let's just talk about some of those public benefits. What are the things that you think about for somebody who has a significant disability? What would you be looking for as a security blanket, whether they're eligible or not, whether or not they use the benefits now. What are those things that you might be looking for to make do? Tom, you mentioned that sometimes people are not aware of certain public benefits that could be helpful to their child. Can you talk about what some of those are?

Emily: Absolutely. So the main one that we see for individuals with disabilities is SSI, Supplemental Security Income, and with SSI automatically comes SSI-linked Medicaid. And so SSI provides a monthly cash benefit which changes each year with the cost of living adjustment. And so the individual receives some money from Social Security, but then also, and almost more importantly, are those medical benefits that come alongside SSI. And that Medicaid can really be instrumental for an individual with a disability who is not able to work and receive medical coverage through their job.

That Medicaid that is linked to their SSI is really vital. And if that SSI money goes away, because they become ineligible due to exceeding the income or the asset limits, the Medicaid linked to the SSI will also be taken away as well. And so we want to ensure that eligibility remains intact for both of those programs. And then on top of that, there are other public benefits that are more, I suppose, social service-oriented such as the Division of Developmental Disabilities, which also requires Medicaid eligibility in order to be eligible for DDD. So those services can be more either vocational-oriented or they can focus on housing and group homes. There are a wide variety of programs that fall under that umbrella, but a lot of them stem around that Medicaid eligibility.

Medicaid often has a $2,000 asset limit depending on the type of Medicaid. If an individual inherits money from a parent who is just trying to do right by their child and that money is inherited outright as opposed to it going into a special needs trust, we've got two problems. Now the individual is not eligible for their public benefits. They could put it in a different type of special needs trust, a first party special needs trust, but then there will be a Medicaid payback. So the ideal situation is to set up a third party special needs trust where the parent’s inheritance goes straight from the parent’s estate into the third party special needs trust with no Medicaid payback and eligibility remains intact for Social Security, Medicaid, DDD, programs along those lines.

Nancy: And Emily, what are some of the conditions or most common conditions you see that cause the loss of the SSI or Medicaid for someone?

Emily: So, as I mentioned, receiving any assets above the $2,000 limit is going to create ineligibility, as well as if an individual is able to go back to work and income starts to exceed that income limit, that could be a problem.

And then the third piece of the puzzle that we often see is called ISM, in-kind support and maintenance. Currently the definition of ISM is food and shelter. So the idea is that the individual's SSI money should be able to cover those two things without a third party such as a family member or a trust paying for food and shelter. And if a family member or a trust by way of the trustee is paying for those items, government will reduce their SSI money. And so it's important. There's a tool in the toolbox that we use. A lease agreement often is a good tool that even if the individual is living with a family member or a parent, a lease can be signed where a certain amount of the money gets paid over to the landlord or the parent. And then the government can raise that SSI money. And so as long as we keep that money as high as possible, we're good. And if someone other than that individual is paying for certain things, then that is where that SSI money can be reduced. And we don't want it to be reduced to the point where they lose SSI and their SSI-linked Medicaid.

Ellen: So that's a good point. A lot of families have heard this concept, okay, I'm getting SSI and I'm supposed to charge my child rent. So you mentioned something about a lease agreement. So I'd like you to go back and explain a little bit more about that, because a lot of families, when their loved one becomes eligible for SSI (and I would also like you to tell us how much that would be), they have heard that they need to pay rent. But help us understand, how should they go about doing that in order to be completely legal, and also have the proper documentation for Social Security when they're asked?

Emily: Absolutely. So, a lot of times it feels a little bit uncomfortable or awkward or silly to be charging your child, your adult child, rent. Of course, you love your child. They're going to be able to live in your house for as long as they are able. But creating that lease agreement with the parent as the landlord and the child as the tenant, even if there's a guardian involved, is a really great resource. So we often go about it - the best way to go about it - is the fair market value for the space that the child is renting; Tom usually suggests $400 or $500 a month. And the way logistically to go about that, that we often recommend to family members, is to have that money come out of the child's SSI money. Again, that is the in-kind support and maintenance that we need to be paid out of the SSI money, taking those four or five hundred dollars a month, whatever is agreed upon in the lease, and setting that into a separate bank account in the parent's name, not in the child's name, because we don't want to go above the resource limit. And then using that bank account that is separate with the child's rent money to pay for things that the parent would otherwise be paying out of pocket for throughout the month. So the little things here and there that, you know, the parent is going to spend otherwise, and it's just coming out of what would otherwise be the child's rent money.

Ellen: So Nancy, you had another question relating to in kind support and maintenance.

Nancy: I do. Some of the cases that we work with, we have beneficiaries that are dual beneficiaries of Social Security benefits. Some receive a portion from Social Security disability and some from Supplemental Security Income. Can you talk a little bit about that - when ISM is involved and there's someone receiving dual benefits and the amount of SSI might be very low?

Emily: So this is where it becomes important to fully understand what your loved one is receiving. It's easy to think of it all as Social Security, but it's important to realize that there are so many different umbrellas underneath the overall title of Social Security. And so, when a loved one is receiving, let's say, a lump sum that's coming in from Social Security of $900 a month, we need to make sure what exactly that is allocated towards, because if they're only receiving $200 worth of SSI a month and $500 of SSDI a month, we need to make sure that SSI is not reduced so low that they are then no longer Medicaid eligible. It's important to understand what is exactly the benefit that they're receiving and that can be done – we call it, or Social Security, rather, calls it – a Benefits Verification letter. You can go on ssa.gov and put in some credentials and receive a letter online that details exactly what benefits the individual is receiving, and if they are being reduced, why they are being reduced. And so that's when we can step in and help create a plan to get those benefits raised.

Nancy: I think that is so important, Emily, because coming back to what Tom was talking about before, families wanting to name other family members as trustees of these trusts, many family members are not informed about these regulations. They're not involved in the application process, they don't understand the rules. So it's very easy for that family member to make a mistake and inadvertently provide a distribution out of that trust that could actually cause the termination of benefits or reduction of benefits for their loved one.

Tom: And the flip side of that is sometimes they don't get benefits at all because they don't realize they're eligible. So in the SSI thing, there's “deeming.” They look at the parent's income and assets to determine whether or not the child is eligible. But when he's 18, they stop deeming. So to get SSI, they could get turned down because they're looking at the parent's income. Parents didn't understand that. So, now the kid's 26. They never went back because they didn't realize that the deeming stopped and now the child would be eligible. Parents have to be aware of that. We’ve seen quite a bit of that, actually.

Ellen: That's interesting. So, we want to make sure that people, even if they've been turned down, they should go back and try again at 18, right, if they've applied too early. That’s a good point. And what is the difference between Medicaid and Medicare? I think a lot of families are confused about those two programs.

Tom: Well, they're both medical insurance programs, but Medicare, you get Medicare if you're getting SSDI, and you get Medicaid if you're getting SSI. And sometimes if your income and assets are low enough, then you can get Medicaid to pay your Medicare premiums. So you want to look at that too as a benefit, potential benefit.

Nancy: If you have a beneficiary on SSI, let's say they began at age 18 with SSI, do they stay on that SSI forever? Or is there an event that could cause him to change that SSI benefit to another Social Security benefit?

Emily: Great question, Nancy. Often when a parent or a spouse of the individual with a disability either dies, retires, or the parent or spouse goes on social security disability themselves, that can be a triggering event where the child or spouse will now be receiving – instead of SSI – SSDI, under the earning record of their parent or spouse. And so that is often when benefits switch.

Nancy: Excellent. Thank you.

Ellen: So, one of the things I have always taken note of, Tom, is that when you talk about estate planning, you always talk about it as a three-pronged approach. There are basically three critical tools that you need to develop or that families need to have a full plan. And what I've heard you say is you need a will, a trust, and a life plan. Would you talk about what you mean by that, and why is a life plan so important?

Tom: Well, a life plan is where you begin. What usually happens, if a family comes to our office and they have three kids, is that they want to leave one third to each of the kids because they love them all equally. And then we sit down and we say, well, you know, Johnny has got a great job with Morgan Stanley and your daughter is, you know, a surgeon, and they don't really need the money, but your son's never going to be able to work and he does need the money. So let's look at what the life plan is, how much is your son going to need to spend to achieve the life that you want for him?

Then we say, okay, now we know how much you want to spend annually, you can probably take out roughly 4% a year from the trust and it'll last as long as he lasts. So now that means you've got to take whatever you're going to spend every year, multiply by 25, that's the number you have to put in the trust.

So then they do that and they say, oh my God, that's 90% of my money. So I can't leave one third, one third, one third. I can leave 95.5, or maybe I don't leave the other healthy kids anything. But you have to do that calculation in order to know how to fund the trust. So your will is going to leave a certain percentage to the trust, but to do the will, you have to do the life care plan first to know how much you need to fund the trust. And it's almost never equal, and probably 5% of the time it's equal.

Ellen: That's really interesting and I think you're right, a lot of families probably start the process thinking, well, I love my kids equally. I'm going to leave equal shares, but you're right. Different family members have a different ability to support themselves and create their own quality of life. So, just another follow up on the life plan - we use the term life plan very comprehensively, and I hear a lot of lawyers referring to a letter of intent. So when you think about the terms life plan and letter of intent, how do you make that distinction? What is a letter of intent?

Tom: I always say that a letter of intent is emotional and a life plan is factual. The letter of intent is “I want my kid to have this, that and the other thing” with no thought of how you're going to pay for any of that. Where the life plan is very detailed, this is what I want, it's not general, and this is what it's going to cost, and where's the money going to come from to pay for it. So, that may be a little harsh and practical, but you have to be practical.

Ellen: Yes, and you're right. You have to be both factual and emotional. So a lot of the planning tools that we see in schools and the adult service system are very, and rightfully so, strictly focused on the individual, and they should be very person-centered. A life plan very often also includes a family member's wishes and dreams and hopes for their loved one because it really is their, in this case, it's their planning for their children. So the family's input is equally important. They know their child, they know what they've been doing for their child all their lives, and they want to carry forward those wishes and hope for them.

Tom: So they make up a budget as part of the life plan and then the budget says, okay, it's going to be X number of dollars a month. So the one we had yesterday, they're going to spend $7,100 a month. So where are we going to get the money to do that? It's fine to say you want all these things, but how are we going to pay for it? So that's the difference between the letter of intent, which is, I want these things. The life plan is, okay, I want them, and here's where the money's going to come from. And often the parents don't have enough money. So then they have to go buy life insurance. So they go buy a term policy because it's cheap. Well, the reason the term policy is cheap is, 94% of the time, the term expires before the parent expires, so they don't collect anything. So they really should buy second-to-die life insurance to make up whatever gap they need to bridge the difference.

Ellen: And what is that? Second-to-die life insurance?

Tom: Second-to-die is if you have a married couple and the husband dies, they don't pay anything. You wait till the wife dies, so it's going to be a longer period of time before the life insurance company has to pay out, but the premiums are lower, so you can afford to buy more, but there's going to be something there when the last parent dies to fund that trust, to carry out the parent's wishes.

Nancy: That's good advice.

Tom: Oh, by the way, on the subject of wills and trusts, if the child has capacity, they should sign a Medical Power of Attorney so somebody else can make medical decisions for them, which is sort of the Guardianship of the Person idea. And then if they also have capacity, the child might sign a Financial Power of Attorney or a supportive decision making agreement so you don't need a Guardianship of the Property.

Nancy: That's good advice, Tom. We meet with a lot of families that do not think about that.

Tom: Yeah, they could do it, they just don't think about it.

Nancy: It's true. So why is it important for families to prepare a will and have it there for when the time comes?

Tom: Definitely before they die.

Nancy: Hopefully.

Tom: And the problem is we don't know when that's going to be. So a good time is now.

Nancy: It's true. So what problems can actually occur if the families do not do that pre-planning and have the wills in place?

Tom: Okay, so the number one thing is if there's no will, and the parent dies, then the money goes by what's called intestacy. So if they're married, it goes to the spouse. But if they're not married, it goes to their kids. So now you’ve got a kid with a disability, just inherited money through intestacy, loses all his benefits. So you want to avoid that. And then people who have children with disabilities, if they get sick, who's going to make medical decisions for them? Who's going to make financial decisions for them? And another big gap is as we get older, there's an 80% chance that we're going to need long term care.

And for most of us, you know, there are things you can do that aren't perfect. But if you've got a disabled child, and you go to a nursing home, and you've got this wonderful life plan, and everything is in place to fund it, but then you wind up in a nursing home at $180-200,0000 a year, your disabled child isn't going to get anything. So, you want to think about that, too. So there's a lot of planning.

Ellen: Absolutely. I think that one of the things that's valuable about this conversation is that we don't know what we don't know, as the saying goes. And so it sounds like one of the things you're doing is helping families to understand what could go wrong and being aware of it and so that they can anticipate and try to put some tools in place to avoid any unintended consequences.

Emily: The big thing here is that it's really just as important for the parents to be preparing and planning for the long term care that they might be receiving in the future, as well as planning for their child with a disability. So it's really a comprehensive plan that when we sit down and have a consultation that we're diving through everyone's lives, and making sure that we are prepared for any scenario, both with the parents, the siblings, the individual with a disability, everyone.

Nancy: When you're drafting special needs trusts for families, what do you have in mind for the things that the funds in a trust might pay for?

Tom: We try to sit down before we do the trust and encourage them to get a life plan, make up a budget. And then we make distributions to cover the things that they want in the budget. We don't try to tell our clients what to do. We give them information, they tell us what to do. So everybody's different. Everybody wants different goals for their kids. The children are all different. They have likes and dislikes, abilities and disabilities. So what do they want? What can they do? So, and what can you afford? So no two are the same. You guys do life plans and I'm sure you've never, you don't use a template. They're all different, right?

Ellen: That's right. Everybody is their own unique individual.

Tom: But basically it falls into three general categories. One is shelter. Where are they going to live, how much is it going to cost, things like, do they want cable TV? We had a guy the other day, he said, my son can't watch cable TV. So we didn't bother funding cable TV. So it's food, shelter, and then the next one is transportation. Can they drive a car? Okay, well then who's going to buy the car? Who's going to pay for the car insurance? Who's going to pay for the gas? All of that. So if they have PLAN New Jersey as their trustee, PLAN would buy the car. They would give them a debit card or a credit card. They go to the gas station, and they’re not going to call PLAN to say it's $50.48. Would you wire it to the attendant? No, you give him a card. They give the card to the gas station attendant, send the receipts to PLAN and they replenish the card.

The next thing is personal. They're going to need clothes, they're going to need shoes. So if they're women, they're going to need more clothes and shoes than guys generally do. And, so how much is that going to cost? Do they get haircuts? Do they like to go to the movies? What do they like to do for entertainment? Everybody always says no, and they say, well, do you get Netflix? Oh yeah, we get Netflix. Well, that's entertainment, so how much do you spend for streaming services, do you like to take a vacation, what medical things do you pay for that Medicaid doesn't pay for?

When you go to the drugstore, do you buy shampoo, do you buy deodorant, do you buy stuff like that? So, we have a whole list that we make up of the things that people typically spend money on. So, that's part of the distributions that should be built in to the trust, but the key is, if it's a special needs trust, the distributions have to be discretionary with the trustee. The child can't say “I want money” and get it. The trustee has to have the right to say no. Now if you get a good trustee, they're going to go over the budget with you and they're going to agree to it, as long as Medicaid will agree to it, and as long as you won't run out of money.

We had a family yesterday getting three and a half million dollars, they had no money at all. So to them that was like three and a half *billion* dollars. So, you know, they're going to spend this money in no time. So you have to kind of, figure out how long is this going to last. So that's one of the restraints. So Medicaid's going to be a restraint. How long do you want the money to last? It's going to be a restraint. But the trustee's not going to get in your way if you can satisfy those two things.

Ellen: Sounds like quite an education, this process of thinking about what are all the things that a person is going to need in the future.

Tom: One of our clients yesterday said, we were told, don't leave the child with anything, don't do a trust, just leave it all to the daughter. And people today said, I don't think that child's going to have any needs. Imagine a child with no needs. So, but they have to start to think about it. And once they do they can understand it.

Ellen: That’s right.

Nancy: Yeah. We find that the trust sometimes becomes an extension of the parents when they're gone. There’s a lot that parents pay all their life for for that child. So they expect the trust to be that extension after they're gone. So we talk about that. What exactly is the parent paying for, and what are their expectations for when they're gone, with regards to the trust?

Tom: I would assume a lot of times you get a family member, like a sibling, to work with you to determine what the child's needs are, right?

Nancy: Correct.

Tom: And that's important. Because my grandson could be starving to death. He's got autism. He's not going to call the trustee and say, I need money for food. He'll just starve to death. So you need somebody who's going to work with the trustee and make sure he gets his food. And I know you guys will send people out and check on them once in a while, make sure they're getting everything they need.

Ellen: Yes, that is one of the things that people plan for when they're planning for what the trust will cover, is someone to check on the individual and make sure, if they're living in a residential setting, they may have staff who can identify their needs. But sometimes not, and sometimes it takes an outside person to help advise the trustee, especially in a situation like your nephew, where he needs somebody to help identify what things would be needed.

Tom: And it's a lot easier for a sibling to do that than it is for the sibling to be the trustee. So a lot of times they don't want to be the trustee, they don't want the liability to be the trustee, but they love their brother. So they'll go visit him. They'll call you and say he needs money for whatever.

Ellen: And what is a legal role that sibling could play so that they are not taking the responsibility of being a trustee and perhaps risking losing the benefits because they don't know the up-to-date laws, but would give them some authority to have oversight over what's happening in the trust?

Emily: There are really two different roles that an individual could play in that capacity. The first one, if the individual with a disability has capacity, that individual can sign a power of attorney document, giving their sibling or their parent, while their parent is alive, power of attorney to act in that capacity.

If the individual does not have capacity to sign documents, guardianship comes into play. And so the sibling can go court, be appointed as the guardian of that person, and then serve in that capacity as guardian, and the trustee is able to work with them as far as distributions go, and other things of that nature.

Now, guardianship does not mean that the individual has to live with their sibling. They can just serve as the guardian and acting on their behalf and making sure that their needs and their wants are accounted for.

Tom: They could also be the trust protector. So a trust protector is somebody who has the authority to remove and replace the trustee. So I always say, you know, the good trustees are good because they are good people. We've had experience, especially since the pandemic, where a lot of people left the trust company they were working with and they're not there anymore and the new people are terrible. So we've had to have the trust protector remove the initial trustee and replace them with another trustee. And we don't do that a lot, but for a while, we did quite a bit with two trustees, where the good people left. You don’t always stay with the trustee you start off with.

Nancy: I would think that also makes the family feel better with their planning because the trust protector would not necessarily be a trustee or have those fiduciary responsibilities, but it's someone who's keeping checks and balances in place with the administration of the money.

Tom: Customer service is disappearing quickly. Especially since the pandemic. Part of it, I think, is corporate greed. They're trying to cut costs and increase profits. But when you've got people with disabilities as beneficiaries of a trust, they need customer service. We all like customer service; they require customer service. So, if you’ve got a trustee who isn't doing their job, get rid of them.

Ellen: Yes, you have a great point. And, all of us appreciate good customer service. We need to know that we're being listened to, and that our needs are being met to the extent possible. And I think there can be a real frustration when there is a trustee because those are the rules of Medicaid and Social Security, that in order to have these public benefits, to retain them, and also have funds to supplement, their lives, the quality of their life. There has to be a third person, a trustee who is making discretionary distributions, but hopefully with proper planning the person can have the best of both worlds.

Tom: You’ve got to look for a couple of things. One, is the trustee caring? Two, is the customer service good? And three, do they know the law of the state they're dealing with? Because we get a lot of trustees who are national and they can be headquartered in Iowa, and they know Iowa law inside and out, but they get a trust in New Jersey, and they have no idea what New Jersey Medicaid law is, and they can do some things that aren't very smart. And it will disqualify the person from benefits, because they did it wrong.

Ellen: Well, that's the real danger, the real consequence. It's a really great point.

Tom: The argument we get from people when we suggest using a corporate trustee is well, that costs money. Yes, it does. But if you don't have a corporate trustee and you're going to have a family member doing it, the family member is probably going to hire somebody to manage the money, they're going to pay them. So the other thing is the trustee is going to invest the money and they're probably going to charge a whole lot less than the investments are going to produce. And if you want good service, you have to pay for it. So it's worth doing.

Ellen: Well, this has been a fascinating conversation and so enlightening. Thank you so much. Are there any final comments, advice, guidance that you'd like to give to families?

Tom: Well, the only thing I would say is we have a pretty good history with PLAN New Jersey, and you've got two people sitting in the opposite side of the table, Ellen and Nancy, who have been doing it for a long time, and you care and do a very good job.

Nancy: Thank you. Thank you, Tom.

Ellen: Thank you so much. Thank you, Tom and Emily, for being with us and sharing your knowledge and expertise. We really appreciate it.

Tom: Thank you for inviting us.

Ellen: Our pleasure.

Emily: Absolutely.

Nancy: Thank you so much, both of you.

Emily: You're welcome.