



## TRANSCRIPT

Episode TWO – Navigating Special Needs Trusts and ABLE Accounts: A Guide for Families

*With special guests Shirley Whitenack, Esq. and Liz Farishian, RN, MA with host Ellen Nalven, co-host Nancy Dilliplane*

Ellen: Hello, my name is Ellen Nalven. I'm the executive director of Planned Lifetime Assistance Network of New Jersey, otherwise known as PLAN|NJ. I'm here with my co host, Nancy Dilliplane, senior director of trust services at PLAN New Jersey. We are so pleased to have two special guests with us today for this PLAN|NJ podcast series on the topics of legal estate and independent living planning for people with disabilities.

We'll focus today's episode on Special Needs Trusts and ABLE accounts. One of our guests is Shirley Whitenack. Shirley is a partner at Schenk Price Smith King and is a nationally renowned trusts and estates attorney with too many accolades and awards to count. Elizabeth Farishian is also with us. Liz is a registered nurse who has worked with people with intellectual and developmental disabilities for many years.

Liz is the parent of a 40 year old daughter who has a mild developmental disability. Her daughter works as an administrative assistant at the school she attended for 20 years. She loves to cook, and she's an exercise enthusiast. I'm delighted to say that Liz is the newly elected president of the Plan New Jersey Board of Directors.

We greatly appreciate you both for being here. We understand that an important part of legal and estate planning for families of people with disabilities is having a Special Needs Trust written for them. PLAN|NJ does provide some basic information about Special Needs Trusts on our website at [plannj.org](http://plannj.org).

Frequently asked questions about Special Needs Trusts are there too. So in this conversation, we'd like to focus more on why these tools are important for families to plan and what they

accomplish for future and current beneficiaries. We also hope to clarify some common misconceptions about how to use these tools for future planning.

So let's dive into the conversation. Shirley, Nancy and I are so pleased to welcome you to the podcast.

Shirley: Thank you for having me.

Ellen: And Liz, we really appreciate your being here to join the conversation.

Liz: It's my pleasure being with you.

Ellen: Shirley, let's start with you. What are the reasons in general that you recommend that families set up Special Needs Trusts or other types of trusts for their children who have disabilities?

Shirley: There are two main reasons why people should consider having a Special Needs Trust when they have a child with disabilities who may not be able to really make a living for themselves and live independently. One of the reasons is to obtain means tested public benefits like Supplemental Security Income, known as SSI, or Social Security Disability and Medicaid.

So that's one reason. The other reason is that sometimes we have people who are high functioning, or the parents don't want them to get government benefits, but they know that their child will not be able to manage large sums of money that they may inherit. So a trust is a very good vehicle for managing money for that person when they can't do it themselves.

Ellen: Okay. Thank you. One common misconception, Shirley, is that the money that remains in trust after the beneficiary is deceased all gets paid back to Medicaid. Is this the case?

Shirley: So it depends on what kind of Special Needs Trust it is. There is what is known as a first party Special Needs Trust, which is funded with the person's own assets. If it may be something that they inherited, it may be the proceeds of a medical malpractice or personal injury matter.

And in that case, there will be a Medicaid payback after the person passes away. But on the third party trust, which is funded with someone else's money, there is no Medicaid payback. So the money can go to whomever the person establishing the trust believes that the money should go to after the primary beneficiary dies.

Ellen: Right. Okay. So that's important for people to understand the distinction. Shirley, you had mentioned that the first party trust would be money that the child inherits directly, but that inheritance would not have been directed to the trust. It would have to be given directly to the person.

Shirley: Correct. It would be an outright inheritance, where the person is actually named as the beneficiary. Or it may be, for example, an estate. In other words, somebody died without a will, and so that person is receiving assets outright. So this is the real reason that it's so important to plan in advance if you have a child with disabilities so that the funds can go into the proper trust.

There is another type of trust as well that can accelerate Medicaid benefits for a parent who needs Medicaid benefits themselves because they need to go into a nursing home. It really behooves that family to speak with an attorney who is very experienced in special needs planning so that they know the various types of trusts that may be used in that particular situation.

Ellen: I see. That makes sense. So that if there is a parent, and there's a child with a disability and the parent may need Medicaid planning themselves, there are ways that the funds can be preserved for the child's needs. Liz, do the reasons to plan that Shirley mentioned ring true for you as the reasons you set up a trust for your daughter?

Liz: Absolutely. Our daughter, as Ellen had mentioned, is really quite high functioning, but when she was little, that wasn't the case. When she was first diagnosed, we really didn't know where it was headed. So we set up the Special Needs Trust quite early in her life. I always laugh, I tell people, my husband and I went to college together, that's how we met. And we took a course in business law. And the only thing I came away with, and I wrote it on my test, my final test, which is why I think I got an A in the class, was that you always need a lawyer. Read whatever you sign and most of the time have a lawyer look at it. So we got caught up with the attorneys pretty early and they had advised us to do a Supplemental Needs Trust, a Special Needs Trust. So we set it up just for the reasons that Shirley had mentioned. And interestingly, her needs changed. When she was quite young, we thought they would be much more dramatic than they are now.

Ellen: Yes, it's also interesting in terms of the need for an attorney. Very often we will hear a family say, "Oh my cousin is a lawyer and so he can develop a trust." Shirley, do you have comments about a family member who might be an attorney developing a Special Needs Trust?

Shirley: Yes. I have seen and reviewed probably hundreds of trusts in my over 30 years of practice where the trusts are defective. And that's because the attorney who drafted the trust really wasn't experienced in knowing how to draft a Special Needs Trust, or may not have been familiar with the particular requirements of New Jersey in drafting those trusts. That's why I encourage people to, in any field, whenever you're looking for an attorney, look for somebody who is experienced in that regard. It's particularly important when we're dealing with trusts for people who have special needs.

Ellen: And what would the result be, or the consequence, of having a defective trust?

Shirley: Sometimes we can fix it fairly easily without going to court, and sometimes we have to do an application in court to make it clear. So, for example, a very common error, as I indicated before, when you have a first party Special Needs Trust, you have to have a Medicaid payback

provision in that trust. You don't do that with a third party trust. I have seen third party trusts that contain Medicaid payback provisions. And so, in that case, the Medicaid agency arguably might be entitled to receive those assets. So we want to fix that before that happens. And if we can prove that it was third party money, and only third party money that went in there, we can often accomplish that. Sometimes it's much harder to do and we have to go to court because we don't know exactly what the circumstances are. The trust may have been written a long time ago, but that's a very common error.

Ellen: Liz, you mentioned that your daughter is doing very well now and she may not need to rely on public benefits. Does your attorney suggest that you keep the trust in place?

Liz: That's a good question, Ellen. One of the things that we've realized as we've gone through this journey is you don't just make a decision when they're little and keep with that decision. You really do need to keep in contact with your attorneys to have your attorney to re-look at things. We have the trust in place. I can't imagine why they would ask us to dissolve that at this point, even though she is doing quite well. But who knows, that's something that we're going to have to go back and review again. Just the way you don't leave your will without getting it reviewed periodically. And also to see if the laws have changed and things like that. So right now, yes, she still does have that trust in place, and we anticipate she will, but that's something we'll have to talk about with the attorney. They really are crucial if you want to make sure that your child is provided for and, like Shirley just mentioned, that you're not giving assets back to the government that really don't need to be paid back. You really do need to be very careful.

Ellen: Shirley, do you have anything to add in terms of families who are not sure whether their child will need to be on public benefits?

Shirley: My philosophy is I hope for the best, but plan for the worst. I will often suggest when people have been diagnosed with some sort of disability that may go through adulthood to set up a Special Needs Trust. It doesn't necessarily need to be funded during your lifetime. So if you don't need it, it's very easy to fix, to bypass it if necessary, but at least it's in place. What I find is that many people do their planning - and what Liz said is very important - I tell people, look at your document at least every three to five years. A lot of people get the document, and it's been a very painful process for them, unfortunately, because they have to think about the fact that they're going to be dying someday and what's going to happen with their child. They don't like to have these thoughts. Once they get it done, they put it away and they don't look at it again for many, many years. So that's why it's very, very important to keep reviewing your documents and thinking about changes in people's lives. Whether the person who would be the beneficiary is getting married, or can function independently and manage their own money, and whether they will need government benefits or not. And sometimes we have people who are fairly high functioning at some point of their lives, but then they may also get Alzheimer's or dementia or other things that will cause the need to continue to have that trust.

Ellen: That's a good point. Life is unpredictable.

Shirley: Yes, it is. I tell people that my crystal ball is broken and I don't know how to fix it.

Ellen: There you go. Let's turn the conversation over to my co-host Nancy Dilliplane.

Nancy: Shirley, when families begin this journey of estate planning for their loved one with a disability, they're often not sure as to what assets or in which ways they can fund the trust. Would you care to provide some insight into that?

Shirley: All assets that the parents have are available to put into the Special Needs Trust. It can be a life insurance policy where the beneficiary is the Special Needs Trust. It can be a Life Insurance Trust that pays into the Special Needs Trust. It can be an IRA, or a 401K, or a 403B plan. We have the SECURE Act now, which is a federal law, which now allows certain types of Special Needs Trusts to be used as a receptacle for those kinds of qualified savings programs. And that's very important these days because what the SECURE Act did is it now says that unless you fit into one of the exemptions, when you inherit an IRA, you have to spend that IRA within 10 years.

There is an exception for people who have disabilities and have a Special Needs Trust, but the Special Needs Trust has to be crafted in such a way that it will be a valid receptacle for those kinds of assets. A lot of people who have children with special needs may not have a lot of money right now, but what they can do is they can buy a second to die policy, which ensures the life of both the father and the mother and pays when the last parent dies. And one of the benefits of that is you don't have to have a medical examination in order to qualify for that. And the premiums are generally cheaper than they are for other types of insurance. So that is something that people often use as a vehicle to fund the trust.

Nancy: Thank you for clarifying that. I'm actually very glad that you mentioned about the qualified assets, like the IRAs, 401Ks. Often parents are not aware that an IRA may be able to fund that trust, and like many of us, we have our own private investments, but also retirement funds. So it's good to clarify that with parents.

Shirley: What I find a lot of times is that people have named their spouse as the beneficiary of those kinds of assets. And then they may not have even bothered with a contingent beneficiary, which means the child may be getting that money directly if the other spouse dies first.

Ellen: They don't know that you can actually name the trust as the beneficiary of that plan, which makes a lot of sense.

Shirley: Correct. There is such a thing as an inherited IRA that can go into a first party Special Needs Trust. The problem with that is there isn't a law saying that's okay, there was what's known as a private letter ruling that someone paid a lot of money to get the tax court can always change that. So it's much, much better to have the vehicle in place that can be used as the receptacle third party trust so that there isn't a payback at the end of it.

Nancy: Let's talk a little bit about the trustee. Parents and individuals who are interested in setting up this third party trust are often wondering who can serve as a trustee. So would you talk a little bit about what that role is and also, in your opinion, who might be the best candidate for the trustee role?

Shirley: A trustee is somebody who's going to manage the assets in the trust for the benefit of the beneficiary and anybody really can serve as a trustee. It can be a family member or it can be a corporate trustee. One of the issues when we have a Special Needs Trust is it's very important that the trustee be familiar with the government benefits that the beneficiary may get. And so if you are naming a family member they may not be savvy in knowing how much can you distribute, for example, to the beneficiary without jeopardizing their ability to receive Social Security benefits such as SSI or Medicaid.

And also, people may not have the experience of managing a great sum of money. So it really depends oftentimes on how much is going into the trust and how much the person either knows or is willing to learn about government benefits and how to protect those benefits. So it really is on a case by case basis oftentimes.

People are very concerned about how much is it going to cost to have a trustee. But what people tend to focus on when they have Special Needs Trusts is what can the money be used for. What people aren't really focused on is how can I make this money make money. How can I make these investments grow? So that even though the trustee may be getting fees, they're still ahead of the game in terms of having more money in the trust than they started with, even though there are distributions, even though they're paying trustee fees, because the money is being managed appropriately.

Nancy: Would you recommend the families have successor trustees listed? And when would that be an appropriate thing to do?

Shirley: I always suggest that people try to name at least two successor trustees, because you may name someone as a trustee that may be unable to serve, they may be deceased, they may be incapacitated, they may have Alzheimer's or senile dementia, something like that. Or the person said, yes, I'll do it, but then when it comes time, they're like, you know what, I changed my mind or I can't do it anymore. If you don't have that, under New Jersey's Uniform Trust Code, there's now a way to name a trustee in a vacancy. Bt that can be somebody that the person who's giving the money didn't want to have manage the money in the first place.

So for people who really care about who is going to be the trustee, I suggest that they do name successor trustees. You can also, by the way, have co-trustees.

Nancy: Wonderful. What are some of the pros and cons. and I think you touched a little bit about this before in one of your other answers, about having the family either be a co-trustee or serve as a trustee. Like I said, you've probably answered some of these concerns before, but would you care to expand a little bit on that?

Shirley: Sure. Some corporate trustees, for example, do not want to serve as a co-trustee like PLAN|NJ, for example. And in that case, however, PLAN|NJ knows that it's very important to continue to have the family involved. And oftentimes the parents or whomever is raising this person who has special needs is very concerned about what if something happens to that corporate trustee, what if they're no longer managed appropriately. The person that they assumed was going to be running the show is no longer there. So what we can do in those cases is we can designate someone as a Trust Protector.

A Trust Protector is somebody who may or may not be a fiduciary, but has a specific role. And that role can be, for example, removing and replacing the trustee. It can be receiving financial statements on a periodic basis. It can be changing the order of the successor trustees. There's all different kinds of things that you can do there. You can decide whether the Trust Protector should be compensated or not. And many of my clients feel much better having a family member in some sort of role, even if they are not serving as the trustee.

Ellen: Yeah, we have a number of - that's becoming a very common practice when, people want PLAN New Jersey to serve as trustee, we suggest that they name a Trust Protector so that a family member can be involved. What are typically the ways that a Trust Protector stays informed about what's going on?

Shirley: Well, that really depends on who the trustee is. For example, if you are having the trust state that the Trust Protector should get periodic financial statements, that's one way they can see what's been going on. Has there been a lot of change in the investments? Are the investments appropriate? Are they losing money? Are they gaining money? What's happening there? Also, one would hope that the trustee is talking to the Trust Protector about certain issues that the Trust Protector should be getting involved in, in accordance with the terms of the trust. We always look to the terms of the trust in the first instance to tell us what is going to happen. And what needs to be done and by whom. So again, you have a certain amount of leeway in terms of naming the Trust Protector.

Ellen: So the trust will define the role of the Trust Protector. Okay. So, Liz, would you talk a little bit about your thoughts as you had this trust written, your thoughts about who would serve as trustee, who you wanted to serve and who you thought would be most appropriate?

Liz: Sure. I think that's an evolving question as well. When she was little, you tended to pick somebody who was relatively close to the parent's age because they were young too. As we age, we're realizing that those things change. My daughter is an only child, so siblings weren't an option. Currently we have a very trusted family friend, and actually we're thinking we do not have a Trust Protector. We're thinking that role is probably better suited for, that role of Trust Protector would be better suited to her. It's a lot to manage a trust and particularly as you age, it becomes more and more - you're dealing with your own health issues and insurance and it becomes a very big task.

So we're thinking of doing more of a corporate trustee, obviously PLAN|NJ, and then putting the Trust Protector in place and doing it that way. Today, if we died, that's the indication that I gave to our current trustee. You call on PLAN|NJ and this is what you do. You let them manage it because it's a lot of work. And even if you get compensated for it, it's still a lot of knowledge that you have to have. You can't mess it up. So, that's the direction that I would think a new parent should go into.

Ellen: Shirley, can you talk a little bit about what could happen if the trustee messes up?

Shirley: Well, there's lots of things that could happen if the trustee messes up. So the question is whether the trustee has breached their fiduciary duty and there are all kinds of remedies for that breach. Sometimes people can self correct. Sometimes it means going to court, but they may have to disgorge their trustee fees, they may have to pay back certain money if they co-mingled the funds. We find often times also, if you have a parent who is named as a trustee of a funded trust, sometimes the parent finds it difficult to separate their funds from the funds of their child because they see it as one big family pot, and that's not the way the law works. So oftentimes the people who are actually getting into trouble are the parents of the trust. Sometimes it's a corporate fiduciary, but it's a very serious thing that courts will look at if it's brought to their attention.

Ellen: Liz, what questions or concerns do you have when you think about your daughter's future financial protections?

Liz: Well, one of the concerns we have, and it's a little bit different for each parent's situation, because our daughter is so high functioning and she does work, but the salary she makes is not going to provide for a lifestyle that we would want to see her have. So we really need to think long term for her, and her assets have to be enough that she will be able to live a comfortable life. So that's a really important consideration. And in fact, while we're blessed that she is so high functioning, it does make it a little bit more difficult than for a parent who has a child who has more of a disability, who may be living in a supervised apartment or a group home where their needs are really provided for.

Ellen: Shirley, sometimes families come to us and they've had a Special Needs Trust written for them, but they're concerned that their child is not on public benefits and may never be on public benefits. So, what's your guidance in terms of how that trust operates and functions for that child?

Shirley: So if it's a third party Special Needs Trust and the person isn't on government benefits, it would just serve as what is known as a discretionary trust. It's a trust where the trustee has the sole discretion to decide what to pay for and what not to pay for. In many cases, people who are not receiving government benefits or means tested government benefits, they may, for example, be getting Social Security Disability, and Medicare. It doesn't matter how much they have in assets. So, a Special Needs Trust may not be as important for them at the time, but they may not be able to manage great sums of money. So that trust would simply operate as a trust



where the trustee makes those determinations. If people are absolutely sure, let's say that person gets a great job and is able to support themselves independently, the money can be distributed. If it is funded or if it's not funded, we just ignore it and change beneficiary designations whether it's in the will or whether it's in insurance policies or in qualified savings so that you're bypassing the trust and the money is going outright to the child. If the Special Needs Trust is not funded and is not going to be used, we don't necessarily need to actually dissolve it.

Nancy: Shirley, some people tell us that they plan to just leave the money to a sibling so that the sibling can take care of the person with the disability. Would you care to talk a little bit about the pitfalls of doing that?

Shirley: Yeah. I heard that much more back in the day. I hear less of that now because more people know about Special Needs Trusts. But I always caution people that leaving the money to a sibling is a bad idea. It's never a good idea. First of all, that person has the legal right to use that money for themselves and not for the beneficiary. If they decide not to give it to their sibling who has special needs, it's too bad, so sad. And It's really a problem.

Number two, if that person who is the sibling happens to die, that money may go to a spouse or to the sibling's children instead of to the beneficiary. So it doesn't make any sense to do that or to put the sibling in that sort of position when it's just so much easier to have a Special Needs Trust.

Now, one of the things that I hear sometimes is, I don't really want to spend the money that I would need to spend to have a Special Needs Trust written. And that, frankly, is where PLAN|NJ's pooled trust comes into play because it's a much less expensive way to deal with the situation, especially if you were going to name PLAN|NJ as the trustee to begin with.

So that is definitely a less expensive option than having a private Special Needs Trust. A lot of times people want the Special Needs Trust because they want to name a family member or they want to have different language in there than the pooled trust. But giving money to a sibling is not a good idea.

Nancy: Now, even if the parents did decide to go that route and leave the money to the sibling, can the sibling then at some point decide to fund a trust?

Shirley: They can. They would be making a gift to the trust. They can certainly do that. I've never seen that happen but theoretically it could and maybe it has.

Ellen: Okay. Where can people get more information about Special Needs Trust to guide them in this process, especially families who are planning?

Shirley: There's a couple of resources that I can recommend. One is the website for the Special Needs Alliance which is an invitation-only group of attorneys from all over the country that have a lot of experience with Special Needs Trusts. There are certain requirements that you need to

have to be a member of that organization. I am a member of that organization. It has a great website with all kinds of resources. They put out a newsletter called The Voice every month on various topics, they also publish what is known as the Special Needs Trustee Handbook, which is a 17 page booklet that can either be downloaded online in English and in Spanish, which basically goes through what you can do with the money in a Special Needs Trust. And there's various other articles and blogs on the Special Needs Alliance website.

There's another group called the Special Needs Planners or the National Academy of Elder Law Attorneys that also have a font of information for people who are considering having a Special Needs Trust. Also the Department of Human Services of the state of New Jersey also has various articles and forms online that you can read.

But I always caution people that when you are looking online, you have to remember that is not necessarily specific to New Jersey. So, I get people all the time saying, I want to do this kind of trust, for example, a lot of people who may have lived in New York or have read about it say, I want some sort of Special Needs Trust where it doesn't follow the requirements of New Jersey. I always caution people, again, you must speak to an attorney in the jurisdiction where the person is going to be receiving benefits because otherwise there could be a problem. But it's a good way of reading up and getting information.

Nancy: Those are excellent resources, and we have used them ourselves. Do you, in your opinion, recommend a particular time when to fund the trust?

Shirley, if you're having a third party trust, there really is not a reason to fund that until death. Because the parents have greater use of the money and they may need it, frankly, for themselves if they need to go into a nursing home and they don't have long term care insurance.

The only time there really is a benefit to funding the trust during the lifetime of the parents is typically when you have a situation where you want to do some tax planning because there may be a taxable estate. We don't worry about that as much anymore because New Jersey, which had a very low exemption amount, had done away with its estate tax in 2018 and the federal exemption for estate tax is very, very high.

Of course, the other way that the trust can be funded is through people other than the parents, so it may be the grandparents, right? Or aunts or uncles, and I often ask people the question, do you think that there is anybody else that will fund this third party Special Needs Trust? I will even suggest that they send a letter to these family members saying, hey, we just did our planning, we want you to know we set up a Special Needs Trust, here's the name of it, and if you want to leave any money to little Johnny, please do so in the name of the little Johnny's Special Needs Trust.

Nancy: Many families worry about the time frame of the funding after they're gone. So they're concerned about how to bridge the gap while the trustee or the estate is collecting the assets. Do you have any recommendations as to anything that can be done to accelerate the funding of the trust?

Shirley: So one of the things that can be done to accelerate the funding of the trust is to put in some small amount of money that will tide the person over for a period of time before they die. Another way of doing it is through insurance benefits because those will get paid out a lot sooner. We don't have to worry about who's qualifying as the executor and other things. The trustee can get that money pretty quickly if the Special Needs Trust is named as a beneficiary. It's usually a matter of weeks once you get the death certificate of the person who died. So there's various ways of doing it.

Ellen: Great. Did you have a comment, Liz?

Liz: If I can piggyback on some of the things that Shirley has been talking about, you can't see, but I'm pushing 70 and still I have friends that are concerned and say, well, no, I'll just leave it to my other child, and I think Shirley's words on that are very, very important. Kids can get divorced, so many things can happen, lawsuits can occur, it's just not a good idea. And the other thing that I thought was interesting that our financial planner had indicated to us was the idea of funding the trust through a second to die life insurance policy. Interestingly, our financial counselor had said to us that we needed that because he looked at our assets and he said, you guys just aren't spending money that you should be spending to have fun.

And we weren't because we felt that the money would be in her best interest when we went. So having that policy gives us a little bit of a clearer head saying, okay, well we can use this money for ourselves and have some kind of enjoyment in retirement and not feel guilty about it. The other thing you had mentioned, and it is an expense, and it's hard if you're having a tough time, but long term care insurance for the parents of a child with special needs, because that can really eat up a lot of the resources. So again, that's peace of mind for us, that if we do need it, it's not going into her money.

Nancy: Great points.

Ellen: That makes a lot of sense, Liz. So we have a few minutes left and we wanted to talk about ABLE accounts, the Achieving a Better Life Experience Act. And, so we have just a few specific questions that we wanted to ask and talk about. First of all Shirley right now, currently the age to have become disabled and therefore qualify to open an account is 26 years old. What if a family doesn't have documentation to prove that they have a disability?

Shirley: Typically, opening up an ABLE account is an online proposition. When you're doing it online, you're supposed to be eligible to receive or actually receiving SSI or SSD benefits. But sometimes people don't have the documentation handy to prove that their child's disability manifested before the age of 26. This is particularly prevalent in mental illness types of issues.

But the opening of these accounts is on the honor system. They're not asking you to actually upload any of the documents that actually prove that the person has such a disability but they could ask for it. I've never heard of anybody doing that - asking for that documentation. They do have the right to ask but typically you don't have to worry about uploading that information.

And typically also if the person is receiving SSI or SSD, there has been some documentation that has been submitted to the Social Security Administration that satisfies them that the person did in fact have a disability. So even if you're using those kinds of documents or some sort of affidavit from a physician or something, school records, but typically that's not going to be a problem in opening up an ABLE account.

Ellen: And what about that age limit of 26?

Shirley: They're talking about having it go up and it very well may be something that happens as far as that's concerned. I think that the ABLE account is going to evolve in different ways as time goes on. It was really designed in the first place to handle small inheritances or other small amounts of money, where people couldn't necessarily spend down because keep in mind that in order to receive SSI or Medicaid, you can't have more than \$2,000 of assets in your name. So if you have some sort of inheritance in excess of that amount, it can jeopardize your ability to get means tested benefits, especially for people who really don't have a lot of reasons right now to spend down that money.

Ellen: That's a very important aspect of this, that resource limits for SSI and Medicaid are typically \$2,000 in assets in a person's name. And one of the things that ABLE accounts do is it provides for more control over the individual's money, more options for savings, and the dignity of having control of your own funds over \$2,000. So let's just talk briefly about the use of ABLE accounts when someone has a Special Needs Trust as well as an ABLE account, what are the benefits of perhaps transferring money from a Special Needs Trust into an ABLE account?

Shirley: One of the anomalies of the Social Security Administration's rules is that if you have a Special Needs Trust and it is paying for housing for the beneficiary, that is going to count as an in kind distribution and that can have the effect of lowering the SSI payment by one third. The anomaly is that if you put money in a Special Needs Trust and you're using the money in an ABLE account to pay for the housing expenses, it does not reduce the SSI benefit. So one of the reasons that we do this is we tell people, put money into the ABLE account, pay the housing expenses in that way, and then you don't have to worry - you can get the maximum amount of money that the person would be entitled to get in SSI benefits. So that's one of the reasons to do that. There's other reasons as well for why you might want to fund an ABLE Account.

By the way, I should just mention right up front that what many people don't know about the ABLE account is there is a Medicaid payback if the beneficiary dies. And so when you are putting money in that didn't belong to the person in the first instance, and that person dies, Medicaid will have a right of recovery against that. So I often tell people this year in 2023 you can put up to \$17,000 in an ABLE account. Maybe you put in a couple of thousand dollars just

for payment of the rent or whatever the housing expenses are going to be, so that you don't have to worry about that payback issue. If the account reaches \$100,000 and the person was getting SSI, the SSI benefit will be suspended until the account goes lower than that.

So there are tricks and tips for funding and using an ABLE Account. The other reason you might want to have an ABLE account is it provides the beneficiary with the ability to spend their own money. Maybe you want to have a couple of thousand dollars in there, you have someone high functioning and they can use that money for Qualified Disability Expenses, QDEs. There's a whole laundry list of things that can be purchased or services that can be obtained through the ABLE account. It's basically whatever that individual needs.

Liz: Shirley, from what you're saying now, the trustee can transfer money from the special needs account to the ABLE account.

Shirley: Yes. That's really a nice feature. Now, if it's coming out of a first party Special Needs Trust and it's over \$5,000, you have to give Medicaid 45 days advance notice, but you don't have to do that with a third party trust.

Nancy: Shirley, would you say that an ABLE account is also a good vehicle if someone who is receiving public benefits and all of a sudden gets a windfall of a small amount, maybe \$10,000 - 15,000, maybe it's a small inheritance or a small settlement.

Shirley: Yes, if they don't have a first party Special Needs Trust. Correct, and they can't spend that money down, then it should absolutely go into an ABLE account. New Jersey has a program, NJ ABLE. You can go online, look at the website, it's very user friendly, a lot of good information. And certain other states allow non-residents to use their ABLE accounts as well. So, in some cases you might want to shop around to see who has the best interest rates or how easy it is to obtain the money because people in New Jersey who want to open an ABLE account aren't necessarily locked into NJ ABLE. They have some other choices as well.

Nancy: Liz, do you see an ABLE account as a good tool for your daughter to use?

Liz: You know, we haven't really thought of that. In the beginning when ABLE accounts first came out, which I'm going to say 5 or 10 years ago there was a lot of uncertainty about what the regulations were going to be. So I sort of dropped the ball on that one. And right now I don't know if she really would need something like that. One of the things that I was thinking about when Shirley was talking though was, I used to work, as a nurse for an agency that did a lot of group homes. And one of the real struggles was how to spend down their money. They would buy 15 pairs of pajamas because they couldn't have the \$2,000. And it was so frustrating for everyone that the money had to be spent kind of foolishly. So if they could put that money in an ABLE account, they could save up and then maybe use the money for something that's truly needed. So I see that as a really good tool.

Nancy: That's a wonderful point. And it's true.

Shirley: It's just another arrow in our quiver of what we can do to maximize people's eligibility for public benefits and also provide for what it is that they need or want that those public benefits don't pay for.

Liz: And it really is critical, particularly with Medicaid, that they stay eligible for Medicaid because that triggers some other benefits like group homes, day programs. You have to be eligible for Medicaid.

Nancy: Absolutely. It's about preserving those very needed benefits.

Liz: Even if they have private insurance through a parent or something like that, you still need to be eligible for Medicaid.

Ellen: Right, the funding is the New Jersey Division of Developmental Disabilities and the individual must be eligible for Medicaid in order to become eligible for the services that the Division of Developmental Disabilities funds, day programs, employment supports and group homes.

Liz: Right, so Medicaid really is critical. One of the things that you didn't mention, Shirley, I want to ask you if this is true. With Medicaid Workability, for those people who are able to hold a job, they can have assets a little bit higher than the \$2,000.

Shirley: That is correct. In fact, they just changed the Workability rules that make it even better and easier. I don't think I've ever said that about any other regulation. There are some good pieces and basically what Workability is, it's a trial period for people who are receiving Medicaid benefits or trying out a full-time job. Some people can do it and some people, it turns out that they're working for a short period of time and they just can't handle the pressure. Workability is a good thing and you can have a higher asset amount. Also, for ABLE accounts, for people who are working in certain fields and don't have the benefit of qualified savings, they can also put some money into the ABLE account that's a higher amount than the \$17,000. So, again, I urge people that should be part of the discussion of the overall planning with the attorney. What tools can we use? What works best in this particular situation?

Ellen: I'm glad that this topic of Workability Medicaid has come up because we're talking about preserving benefits because the benefits, specifically Medicaid, are required to fund some of those essential personal support services - any kind of residential supports, day program supports, even in some cases supported employment, and the fear is if you lose SSI, Supplemental Security Income, you may automatically lose Medicaid because they are connected. So this Workability Medicaid program through the Board of Social Services or through the Division of Disability Services is so essential because you can still work, still eligible for collect Medicaid benefits, still be eligible for the Division of Developmental Disabilities, and be employed. Employment is such an important factor for all of us, such an important role. We become dignified members of the community; we earn money, we pay taxes. So we want to

promote employment, but we also know that we've got to have this balancing act of protecting these benefits. Shirley, Do you have anything you'd like to add to our conversation at this point?

Shirley: I think that it's very important for people to think about the various ways that they can help their children when they're gone. One way that people can do that is to have the correct comprehensive planning that they think they don't need. What people often don't realize is they are actually financially worth more dead than alive because they may have insurance and people tend to purchase a lot of insurance when they have children with special needs. And so it's very important to have a team of people that you're working with, accountants, financial planners, attorneys so that you can be assured that your child is going to be taken care of, at least from a financial perspective, when you're no longer able to be there to do that.

Ellen: Liz, Is there anything else you'd like to talk about?

Liz: I kind of feel that we keep on repeating this, but as Shirley had said, it is gut wrenching to have to go through this process, meet with the attorney. You know, you might have stabilized things and maybe scabbed over emotionally, and you meet with that attorney, boy, that scab rips right off. You have to name all these people. And it's a very gut wrenching experience. But you need to do it. You need to go into it knowing that it may be a little bit painful. But when it's done, you can put your head on the pillow at night and rest a little bit easier.

Ellen: Shirley Whitenack, Liz Farishian, we cannot thank you enough for your time, your expertise, and for sharing this really invaluable information for families and people with disabilities. So we thank you very, very much.

Nancy: Thank you. Thank you both.