Special Needs Spotlight Webinar Series: Integrating Financial & Legal Planning for Families with a Child with a Disability

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The law firm Norris McLaughlin, P.A., is pleased to present the second session of the Special Needs Spotlight Webinar Series, “Integrating Financial & Legal Planning for Families with a Child with a Disability.” Shana Siegel, a Member of the firm and Chair of its Elder Care & Special Needs Law Practice Group, and Elizabeth McKenna, CFP and Chartered Special Needs Consultant at Merrill Lynch Wealth Management, spoke on financial, estate, and other legal planning for families with children with special needs.

Special Needs Estate Planning

Shana Siegel: I am the Chair of the Elder Law and Special Needs Group at Norris McLaughlin and I’m here today with Beth McKenna, who is a CFP and Chartered Special Needs Consultant and a Wealth Management Advisor at Merrill Lynch. Beth
and I have worked together with the number of families and often there is a hesitancy to plan. Especially, people get involved in the kind of day-to-day and get overwhelmed, so we wanted to kind of give a little bit of background about how to integrate legal and financial planning. So, let’s get started.

So, if you are here today we’re watching this then you’ve overcome this desire to put your head in the sand and not focus on these things. So, that’s a wonderful first step, because obviously, if you don’t plan things aren’t going to go the way we need them to. For parents who have small children, we really advise them to keep it simple. Focus on their own estate planning documents and then you can layer in additional things as we go along. So, that really starts with focusing on your power of attorney. We’re going to talk about these in detail. Your healthcare, a will, with obviously special provisions for special needs, and the one that is often left out and forgotten, is beneficiary designations, really a key.

So, a lot of times people think that any power of attorney will do, but many times when I review powers of attorney that have been drafted previously by other attorneys or something that someone’s gotten off of the Internet, they don’t include some really important provisions. They need to include a broad gifting power so that if something happened to you, your agent would be able to make gifts and provide for your child with special needs, as well as the rest of your family.

It needs to include the authority to create and fund a trust. Often, even if you already have a trust in place, you may need additional trust and certainly may need to fund that trust and if you lose capacity, you want your power of attorney agent to be to do that on your behalf. It should include the authority to resign and appoint a trustee, a guardian, or whatever fiduciary roll you may have for your child. And that way, again, if you become incapacitated unexpectedly, your agent can step in and either take on that role themselves or be able to wait someone else to do so. In drafting your will, it’s important, if you have a minor child or if you have a child that may be incapacitated as an adult, that you designate a guardian.

If you designate a guardian for a minor child then that person will be named by the court unless there is some obvious reason why they can’t. If you designate someone as a guardian an adult—you are a guardian for your adult child—that will be taken into consideration by the court, but they do have to take an affirmative step to be able to appoint someone as Guardian, it doesn’t happen automatically. We recommend that you have references to a special needs trust within the will, obviously, and that may be a special needs trust or, in some situations, it could be a simple discretionary trust. It really depends on the individual situation of your child, the trustee, the level of sophistication of the trustee, and whether they need that additional guidance of a special needs trust, whether your child is likely to be on means-tested benefits. What I’m working with clients I have a discussion with them about whether they want to have a trust within their will or whether there will pour into a separate standalone trust. I generally recommend that if possible they do a separate standalone trust because that trust will already be in existence and we’ll just be looking at adding funds. And that can really expedite things and avoid any delay in the funding that might otherwise occur. Sometimes clients choose to just have a trust under their will and that is often more economical. The problem with that is that that trust can’t be funded until after you pass away. So, if there are other
family members who want to leave money to your child, there isn’t really a mechanism there for them to do that except for creating their own separate trust—and then you might end up with a number of different trusts for your child, which just gets more complicated. So, it’s best to just create that standalone separate special needs trust. It doesn’t necessarily have to be funded, and then have within your will, have it pour into that trust. It’s important to think about the distribution between your child with special needs and any other children that you may have. And we’re going to talk about that in more detail when Beth joins us as well.

So, when we talk about third-party trusts, and that is the type of trust that this is because it’s funded by a third-party—you—not by the child’s own fund. And in a future webinar that we do, we’ll talk about the distinction between first-party trusts, pool trusts, and third-party trusts.

However, for right now, we’re talking about a third-party trust. You can give the trustee wide latitude in how to make distributions. It doesn’t even necessarily have to be a special needs trust, it doesn’t necessarily have to have special needs language, although we do recommend that because it does provide better instructions for the trustee and is less likely to be attacked by the government.

When we’re doing a third-party trust—and the importance of having it in your estate planning and the importance of doing all of this planning ahead of time, is then there does not need to be any payback provision to the state for DDD or Medicaid services. If your child inherits assets outright, say you forget, and they’re named as the beneficiary on an account or on your IRA, or your life insurance, and so they inherit those assets outright, then if those assets then need to go into trust, that’s going to be a trust that has a payback provision. So, it’s really important to plan ahead and avoid that.

One of the most important decisions that you’re going to make in terms of doing this planning is who’s going to be your trustee. And when we’re thinking about trustees, you need to think about over the lifetime of your child. Because that may be decades, quite a long time. So, you need to have layers of trustees. You may think that right you’re going to be trustee or maybe your spouse or a sibling is going to step in next, but you really need to think about the future. At what point may that not be necessary. Your child’s siblings may have their own children, their own responsibilities and it may be very difficult for them to act as trustee. It may also not be a great idea just because sometimes they can get in the way of the relationship between the siblings. So, you need to think about who that backup entity or person may be. Some people will choose a private trust company or a trusted professional to be a backup trustee. Sometimes people are uncomfortable having just an entity or an organization involved as trustee, and you can certainly do a co-trusteeship between an organization, such as a trust company and a family member.

But the other option that many people aren’t aware of is something called the trust protector. And what a trust protector is, is someone who is not serving as trustee, so they really don’t have the day-to-day responsibilities that a trustee has; however, they are there to look out for the beneficiary. They can be reviewing bank statements, making sure that the trustee is acting appropriately, and generally they are given the ability to remove the trustee if the trustee is acting inappropriately.
This may be a role that you may want to have for a family member. If you don’t want to have them take on that day-to-day responsibility, or if you’re going to have a family member be the trustee, then you might have a trusted professional acting as trust protector just to make sure that everything is going smoothly, and that the trustee is following all the rules that they need to follow with regard to public benefits. So, this can be a real help if you have a less experienced trustee, who may not have all the knowledge about public benefits. Having a trusted professional like an attorney as the trust protector can be really helpful.

I often discussed with my families whether they want a revocable or irrevocable trust. Revocable means the trust can be changed at any time during the parent’s lifetime. So, if I were to create a trust and fund it for my child, I might decide that some of the provisions need to be tweaked as that child ages and as I age. And that would be the benefit of having revocable trust. When you want to have an irrevocable trust is if you are going to fund it substantially now. At that point, there may be some advantages of making it irrevocable for your own tax planning purposes. And that’s a conversation to have with your attorney.

One thing that we are careful to do is to create a trust that is going to become irrevocable at the time that the parent dies. And this is going to allow it to convert over to qualified disability trust. A qualified disability trust, which we’re going to talk about in much more detail in a future session, is a trusted that has a lot of tax benefits. Many of you may know if you have a special needs trust that it can have a not so favorable tax status. So, if you have a trust and trust is paying taxes, it is going to pay taxes at a fairly high tax rate. So, when income is just reaching a fairly low level it would create a high tax burden. If we can qualify our trust as a qualifying disability trust, which is very easy to do, but it has to be an irrevocable trust to do that, then we can have the trust pay taxes just like it’s an individual. So, that can be very advantageous. So what language I put in my trust is that it converts from a revocable trust during the parent’s lifetime to a qualified disability trust once that parent passes away.

So, these are just some of the considerations that you need to think about when you’re drafting these trusts, and so you can see why it’s important to work with a professional who really understands the ins and outs of these documents. Once we have a trust, now we need to really think about how we’re going to fund it, how much do we need to fund it, and for those issues, I’m going to turn it over to Beth.

**Special Needs Financial Planning**

**Beth McKenna:** Good afternoon everyone. So, thanks to Shana’s great work we would now have all the estate planning documents needed, including the all-important third-party supplemental needs trust. The question now is, how do we fund and how much do we need? That’s my job. Next slide, please. Next slide.

As with all planning, it’s really best to talk with a professional with the expertise and knowledge of your particular circumstance to advise you. We also want to make sure that your entire family is involved in the process of putting this financial strategy in place. Next slide.

So, step one: We need to—So, this is where we start with my family’s. We define how
you see your loved one's life going after you, the irreplaceable parent, is gone.

Step two: We want to make sure that your assets are used as efficiently as possible to preserve your loved one's quality of life. We will measure the gap between the anticipated government benefits and what you think that ideal life for your child will cost. And we spend a lot of time with that. So, I call this planning over lifetimes because that is what it literally is. I cannot adequately project for the future your child without actually doing two plans. One for you, and one for your child. We also have to take into consideration all goals for the family, including retirement for you and the education of your typical children, for example. So, the level of complexity of a special needs family financial plan really approaches the complexity typically seen in ultra-high net worth scenarios, believe it or not. And it really needs to be treated that way.

Finally, we want to do our best to preserve your estate for your family or charitable goals. As Shana actually mentioned, if properly administered, a third-party supplemental needs trust can be left to remainder beneficiaries, such as your typical children or charities after the death of your loved one with special needs. Next slide, please.

So, first I actually start with my families with our special needs planning workbook. I ask my families to gather all the information on benefits. Also, on what your child enjoys and the cost of those supplemental benefits. Does your child, for example—Does your child like to go on vacations? What activities does he or she enjoy? For example, I have an 18-year-old son, Michael, who has special needs. Michael loves monster trucks. So, I know every year, I have to build into his plan at least one visit to see Monster Jam. Also, he loves the New York Giants, so a couple of games a year, at least, have to be built into our plan.

We want you to consider bringing all family members into the process and place your child at the center. We want your child to participate in the process as much as possible, as well. It’s really important, this is above all, to keep others in the loop. So, for example—I always use this example: Grandma loves your little boy or girl so much that she leaves money to that child at death. Unfortunately, grandma didn’t know that there was a special supplemental needs trust available, and so she leaves the monies to the child in the child’s name. That’s something that we want to avoid, always. We want you to create a letter of intent and a life plan. Now, I’m going to go into that in a lot more detail in the future—a future webinar. But, suffice it to say, that the letter of intent is as complete a picture of your child’s current situation as possible, including medications, behavioral plans, again, the things in your child enjoys. And then the life plan is more about the hopes and dreams you have for your child in the future. Often, permanent life insurance is the best way to provide funding for part of the money needed, while preserving assets for other goals. Next slide, please.

So, this is how we put it all together. With my wealth outlook planning tool, we basically back into the amount needed for the supplemental needs trust by weighing basic living expenses, plus supplemental needs for a child’s overall quality of life. And then we work that against the anticipated government benefits. Of course, as Shana mentioned, the supplemental needs trust should be used to hold these assets never in a child’s name.
You can also use achieving a better life experience able account to support your loved one’s lifestyle. We’re going again to go into that in future webinars, so I’m not going to go into it very much here. It is a 529-like plan. And if you want more information on that, you can go to www.ablenrc.org. Next slide.

So, as I mentioned, use of life insurance that is permanent life insurance, not term, but permanent, we have to make sure that is going to last your entire lifetime. It actually creates leverage that assists in extending those assets over two lifetimes. And, as Shana mentioned prior to this, beneficiary designations must be accurate, so we must make sure that the trust is the beneficiary on the life insurance beneficiary document.

And with that, I’m going to hand it back to Shana.

Special Needs Legal Planning

Shana Siegel: Thank you. Yes. So, I just want to drive home the point about beneficiary designations. I have a client right now, who I am working with. The parent of a special needs child. The grandmother just passed away and she did incorporate a special needs trust within her will because she did have a discussion with her son about that. He consulted with me, and she was able to make an amendment to her will and, so most of the funds are going to go into special needs trust for her grandson. However, she forgot about her IRAs. Her IRAs had the beneficiaries as her grandchildren, so a substantial amount of money is going directly to him as a result. We are trying to work with the company to be able to have those assets into a special needs trust. It will, unfortunately, need to be a first-party special needs trust, but. So, we have one problem of, we have a payback. We have a second problem that it’s difficult to do a custodian to custodian transfer, to be able to not have to liquidate that IRA. When you have a named trust in this situation, where the trust wasn’t actually named. So, we actually have not just the payback problem, but we have a tax problem that we’re trying to override in this situation. So, it can be really, really costly to not check all of those beneficiary designations.

So, I just wanted to touch for a moment here about the Secure Act. You may be aware of this. This is an Act that passed recently that changed the inheritance rules for all retirement accounts—for qualified retirement accounts. And what it did was that it limited tax deferral of inherited retirement accounts. So, what typically what happened before this law was, if I were to leave the retirement account to my child, that child could then stretch that retirement account over their lifetime. Meaning, that they can take the minimum distributions based on their entire lifetime, rather than based on my life expectancy. And that was a really great tool to be able to allow that money to grow over a second lifetime. However, now that has been limited under the Secure Act. It limits the amount of time that you can keep the funds in an inherited retirement account to ten years, instead of it being over the beneficiary’s lifetime. So, you can see how that is, you know, less than ideal. You’ve only got ten years to take that money out. There is an exception in the Secure Act for individuals with special needs, as well as for special needs trusts. So, that actually kind of turns on its head some of the advice that you may have been given in the past or, Beth and I, often will have given families about what to do with retirement
accounts. We typically would advise that retirement accounts should go to the non-special needs beneficiaries, but now that doesn’t make sense. Now it makes sense to take advantage of the strategy for the special needs beneficiary and perhaps other assets to your typical children. So, it’s important to do that though there are very specific rules to make sure that you do qualify for this. And there are exceptions within the Secure Act as how this trust is to be structured. So, for example, you may have third-party special needs trust which allows the trustee to make distributions for the individual or for their children. That’s a fairly common provision. However, that would be a problem under the Secure Act. So, we may need to be reviewing our special needs trust, we may need to be reviewing all of our special needs designations as a result of this Act. I’ve already for a number of clients done some work in this area where I’ve had to change things. So, that’s something to review if you do have documents in place already. And as I said, you know, make you think about how you’re going to distribute assets between your family members at that point.

So, I just wanted to give a little bit here about public benefits and, you know, when you’re thinking about what your source of funding for your child’s future is, I’m not going to go into a lot of detail here, but I just wanted to kind of give a quick summary of these sources of public benefits. And you know, you are probably familiar with some of these.

So, when we look at SSD, that’s Social Security disability, that is disability based on your child’s own work record. So if your child is working then they will earn Social Security credits over their work history and then they could—if they then became disabled or their disability then forced them to not be able to work anymore or for some period of time, they would be getting SSD on their own work records. And a lot of times people don’t realize that because a child may start out with SSI due to their special need, but then they are working, and then over time that may shift. SSCDB, which we all kind of think of as DAC (Disabled Adult Child) is now Child Disabled Beneficiary, that is where a child receives Social Security on your work record. So, when I retire my child with special needs would be able to receive Social Security based on my work record. And there is no means testing associated with these first two benefits. So, if your child is receiving these two benefits and only these two benefits, then we don’t have to worry about whether they are keeping their assets below $2000, they could have more. The rest of the benefits that we’re talking about here all have means-testing. So those are where you really have to be very careful about distributions from the trust. So, we have SSI, a child may be on SSI. Typically, once they hit age 18 and they are disabled, if your child is DDD eligible, they could be on the Supports Program where they could be on CCW, and that’s where a large amount of their funding for their supports that they have, or their housing may come from these two programs.

Many clients are on Medicare and they would be Medicare, usually in addition to Medicaid, if they have SSD or DAC. So, if you have a child who is under those Social Security programs then their health insurance might come through Medicare. However, you’re also going to need them to be on Medicaid in order to receive the supports under DDD, if that is at all possible. Though DDD always wants individuals to be on Medicaid where possible. And, so often, we’ll have dual eligibles. An individual who is on Medicare and Medicaid. And Medicaid along with SSI is where
you’re getting all of those limitations in terms of how you use the special needs trust; are using it for food and shelter; how that impacts the income rules, and we’ll be doing a separate webinar which will go into that in much, much greater detail and we’ll be able to kind of walk you through all of those very confusing rules, because I know people have a lot of difficulty dealing with those issues. So, we’ll address that —when you have some time, you’ll be able to sit down go through that, and find a lot of people have to go through that couple of times and as issues arise, and that’s why we’re doing recorded webinars, so you can do that whenever you need to.

I wanted to also just mentioned that there’s a child support termination law that came into effect last year which is pretty important, and if your child is receiving child support that is going to end at age 19, unless the custodial parent requests an extension and is able to cite specific reasons. Now disability is a reason here—disability prior to age 19. But that is only going to get you an extension of child support to age 23. That’s a big change. That’s not the way it had been previously. We saw people who are on child support for many, many years. Now we cannot have child support beyond age 23. That doesn’t mean there cannot be any financial compensation. It just means that it is not going to be through the Probation Division and through Child Support anymore. So, that would be a situation where you would want to sit down with your attorneys and really determine with your ex-spouse if you have a good relationship and determine what is the best approach. Sometimes it makes sense to continue with financial maintenance. Sometimes it does not, and it makes sense to have direct compensation, direct payment of certain expenses because then you’re not looking at an issue with impacted public benefits. Sometimes it makes sense to have direct funding of a special needs trust. So, those are all things that you need to discuss with your attorney, with your ex-spouse, and really understand what the implications are for public benefits.

If you’ve been working with a family law attorney that does not have a background in public benefits, you need to loop another attorney in to be able to consult with them, so that they really understand this—because, you know, this can cause all kinds of issues when you’re looking at change from child support to another type of financial maintenance. And this is, you know, going to happen for everyone as they’re hitting that age 23, so you really want to plan ahead with that.

So, lastly, I just want to allow to address some transition planning. Certainly, all of the things we’ve been talking about, you need to think about as your child ages—but, as they hit age 18 and come into adulthood, there are some additional things that you need to be thinking about. Whether or not you’re going to be the guardian for your child when they hit age 18 or whether your child can and should execute a power of attorney and a healthcare proxy. Certainly, there are many children with special needs who can execute these documents. For some who can, it may not be the best and most appropriate approach because they may be vulnerable to exploitation and that may be an issue that having guardianship may be a better solution for them. So, that’s really something to talk about with your attorney weighing those pros and cons of the various approaches. Where appropriate, a mental health advance directive can be really important and really valuable. So that your child’s wishes and experiences on psychiatric medicines can be taken into account and potentially you can have the ability to be able to voluntarily commit your child if that is appropriate. If you do have those types of issues with your child,
then you may want to find out more about a mental health advance directive. Certainly, registering with DDD and, if appropriate, with Division of Vocational Rehab Services is something that is very essential at that stage. And then, again, as you age and your child ages, you may be able to get on the priority list. So, that’s important to stay in contact and to notify them as you are aging, so that you’re able to move up onto that priority housing list. And then, also public benefits. As we talked about, often time individuals are eligible at age 18 for SSI. And so, whether or not to do that, to apply for SSI, would be a conversation to start having ahead of time. And to get ready to do so, you may need to move some funds into a special needs trust if your child has funds in their name at that point.

So, these are all steps that you can take to avoid some of the crises that we see all the time. Unfortunately, Beth and I do end up playing cleanup sometimes where families have not thought or, you know, made a mistake and missed certain assets. And we know that preplanning always going to give you a better choice, it’s always going to save you money to do those things upfront and really ensuring that the assets are there to provide for your child and that you are not impacting negatively your own retirement, your other children’s needs for education and inheritance as well.

So, we’re here to help you avoid costly mistakes and hopefully, this has been helpful to be able to have you think about how to protect your family. Anything you want to add, Beth?

Beth McKenna: No. Just thank you for joining today, and as Shana said, we are here to help.

Shana Siegel: Thank you.

Watch the recording here.

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