



## AMDA Conference Call Transcript

### Session No. 8: Special Needs Trust Funds

**Speaker: Theresa Varnet**

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**Bio:** Theresa Varnet is an attorney with Spane, Spane and Varnet. She works with trust funds and how to set up a trust fund for our loved ones. Her office is out of Chicago, IL.

I am always glad to share information. I do a lot of training across the country so this is something that I am used to doing. One of the things is when you have a child who may need government benefits, even if you don't know for certain that they are going to need government benefits, that you want to do when you set up an estate plan which is a will or a trust. Is to make sure that whatever you set up for your son or daughter doesn't disqualify them for critically needed benefits and the only way to do that is with something called special needs trust or supplemental needs trust. The beauty of a supplemental needs trust is it can receive anything that anyone in the family wants to leave, whether it is grandparent, an aunt, uncle or friend of the family whatever. Those funds can be held throughout the beneficiary's lifetime. Supplementing their care, filling in the gap, paying for things the government doesn't pay for or paying for a higher quality for services that are above and beyond what the government provides. And then when the individual, who is the beneficiary of the trust, passes away, that money goes to charity or wherever it is that the family that set up the trust in the first place says it goes.

So, there's really a lot of people are afraid to put money in these kinds of trusts because they think the government will get the money when the beneficiary dies, but that's not the case, it can go to other family members, it can go to other children in the family. Or it is a nice way to leaving a legacy in your child's name by leaving it to charity.

I would just open questions on any topic at all in terms of funding trusts through wills or life insurance policies or whatever, but that is very basically what you need to know about supplemental needs trusts. They will just receive the inheritance rather than the inheritance going directly to the person with the disability. I should back up and explain; if a person with a disability has more than \$2000 in his/her name they will not qualify for a needs based, which is welfare type programs like Medicaid.

**Q: Ok can you say that again, I'm sorry.**

**A:** If a person has more than \$2000 in his/her name, they will not qualify for any government benefits that are needs based.

**Q: So it has to be in the child's name though? What about if the parent has that?**

**A:** Well if a parent of a child under the age of 18 has assets, the most needs based benefits the parent's resources are counted. Once the child turns 18, the parent's assets and income are no longer counted. When most people are thinking about doing the estate plan, they are hoping



## AMDA Conference Call Transcript

that they are going to be in their ripe old age of 70 or 80 and their adult disabled child will be 40 or 50. We are talking about adults for the most part. However, even grandparents who want to provide for the children/grandchildren with special needs could leave a special needs trust, but up until the child reaches 18 his/her parent couldn't be the trustee. So you could still have a grandparent doing this for a family and just not putting the money into the parent's name so that the money wouldn't count against the handicapped child.

I have a client right now, as a matter of fact, who's daughter is in her early 30's and she has a grandson I believe he is 9 or 10 years old and the grandmother has cancer. She wants to provide for her daughter and grandson. She knows that if she leaves money to her daughter, who is poor, her daughter will lose all the government benefits and assistance she is getting for her son, who has a significant disability. So she has set up a special needs trust for the grandson and until her grandson reaches 18. The mother can't touch the money herself it will be managed by uncle by her brother for the nephew

So you can provide for children as well you just have to be a little more careful on how you set it up.

Has everyone had a chance to read like the basics on my website on the terms of a special needs trust is?

No, I apologize I saw the memo to do that and meant to do that and forgot all about it. I will do that right after the conference.

The only reason I say that is I knew in an hour phone call if we asking any questions that it would be very hard to try to explain what it is. That is why it would be helpful to have it ahead of time. Basically what all it is a way of providing money, an inheritance, for a person who may need government benefits at sometime in their life. The government can't claim it as a resource because it doesn't belong to the disabled person. The trust will have language in it like that will say something to this effect "the primary purpose of this trust is to provide those goods and services only that the government doesn't provide or to provide a higher quality of care than that which government provides." So you get the government's subsistence level as a base and then the special needs trust comes in with a quality piece.

**Q: You said that if the beneficiary of the trust dies, for example this child, was set up for, then the trust can be redirected to other children?**

A: Yes. If it's a third party trust, if the money in the special needs trust does not belong to the handicapped person to begin with, then yes. I am assuming that is what we are talking about here. There is a little known, and I don't know how long ago habit, because there are people right now in Washington who would like to take this away from us, but if a disabled person is under the age of 65, comes into a windfall from any source via an inheritance, lawsuit settlement, lottery winning whatever,. He/she can take their own money and put it in a trust for themselves it is called special needs trust, but because the trust is funded with their own money it has what is called a payback to the state. In other words, when the handicapped child dies,



## AMDA Conference Call Transcript

if there is anything left it goes back to the state. That is what we call a qualified special needs trust. It is used in very rare circumstances.

I didn't think that was the focus of tonight's phone call. I thought tonight's call was parents planning with their own money or grandparents planning, but if somebody does have any money in their name from a lawsuit settlement or whatever, there is additional information on my website under OBRA (Omnibus Budget Reconciliate Act) 93 Trust. That type of trust we only use in two circumstances.

**Q: Can they use the full trust available to them, or just the interest or just the dividends?**

A: Everything of it including the principal. That is up to what we call the settler, the person who creates the trust, but generally a pure special needs trust allows the trustee to dip into the interest as well as the principal. You could limit it if you wanted. If somebody wanted to set aside a nest egg for a disabled grandchild, and then wanted to go to the other grandchildren after the beneficiary died they could just limit it to the income, but there's no rule about that. Most parents say that the trustee can dip into the income and principal at the trustee sole discretion.

Everyone who has a child with special needs, quite frankly should redo their will and provide this, even if in 20-30 years later it turns out the child doesn't need benefits. You can always go back in and change your will and leave the money directly to the beneficiary, but I tell people that if they think their child may need government benefits, we don't have a crystal ball as to when we are going to die. So why not have it set up and that way you can designate you're IRAs, retirement plans, life insurance policies, whatever so they flow into the special needs trust. Because, God forbid, it does happen early. You're prepared.

**Q: You said that it is not the ownership of the beneficiary, that they are also for eligible for Medicare/Medicaid?**

A: Yes, there are basically three types of government benefits. There are your entitlements which Medicare is, your welfare benefits which Medicaid is, and we now have what we call a buy in medicate for people who go to work and lose their Medicaid because they are making too much money, but they are allowed to buy in and that is called a sliding scale C program. So we now have three types of medical coverage in the United States one of which is an entitlement which is Medicare, one of which is welfare which is Medicaid and the third is sliding scale C by that I mean you based pay on your ability to pay and how much you can earn depends upon what state you live in because all the states have adopted different caps.



## AMDA Conference Call Transcript

Here, I'm in Massachusetts right now when Marsha introduced me she said that I was from Illinois. My main practice is in Illinois, but I live in Massachusetts and in Massachusetts you can earn almost \$40,000 a year and still be able to buy into Medicaid. In Illinois, the cap is \$22,000 a year. So as you can see that is a pretty big difference. So it just depends on which state you are in and all the states you can't assume what a state does today their going to do tomorrow. The states are in a period major flux so who you have as your Governor, who your state representatives or state senators they make a big difference, it isn't all just federal.

Anybody have any questions for Theresa?

**Q: How old are your children? I have a daughter with special needs, but she is now 21. I don't think that she would come under this at all anymore. Of course, it is something that would have been beneficial.**

A: Why wouldn't she come under these programs now that she is 21 your income wouldn't be counted now. Your income wouldn't be counted now. She should be getting SSI and Medicaid right now. Is she? No. Is she working? No She is in school. Ok if she has a disability that prevents her from working and here is the definition that social security uses, if you have a mental or physical impairment that prevents you from being gainfully active, then you are entitled to SSI. SSI will give you approximately \$550 a month plus Medicaid which pays for your prescriptions, your co-pays and everything, and if she is not working. Do you have group health insurance? For yourself. We have a personal policy. Not a group policy. Well if anyone is lucky enough to have a group policy. Then that group policy will pay for that child forever. My daughter is 37 and she is still covered under my husband's health insurance policy. She's got the best of all worlds. She has Medicare because she's worked and paid into social security. She got Medicaid because she is also still poor since she only earns \$6,000 a year. Because she is what we call a Disable Adult Child (DAC), she is eligible to stay under my husband's insurance. So we have all three coverages for her. So it provides an excellent health insurance. A lot of people think once the child moves out of the home they can never claim them on their health insurance. My daughter lives in a home of her own, but because she was disabled prior to the age of 22 and she is incapable of gainful activity we can still cover her under our plan. That is true for most group insurance policies. So your child who is 21, if you have a personal plan unfortunately it will stop covering her probably when she ages out of school, but she still should be eligible for SSI and Medicaid because your income and assets would not count anymore

**Q: Excuse me I have one question on that. Is there like an income limit for the child once their over 21 and you want to cover the on your group insurance? Is there a limit to what they can earn?**

A: As long as they are getting SSI, they are eligible for your group health insurance because SSI is what we call prima facie evidence that their incapable for gainful activity. Now SSI generally looks at whether or not the individual can earn more than \$810 a month. Now it gets more complicated than that because there is something called impairment related work expenses. So I have a client who is earning over \$1,000 a month, but he has to pay for a medication that costs him \$400 a month that Medicaid won't pay for. So if you minus the \$400 from the earnings of \$1,100, he has less than the \$810 countable income because it is call impairment related



## AMDA Conference Call Transcript

work expenses you can deduct them. So it comes down to \$810 a month of countable income and then he qualifies. So I hate to say it is just \$810 a month because a person might have some deductions and they could earn more, but it's a good deal if your child works. Like my daughter works part-time, she works three days a week and it's just perfect for her it's just enough that she gets enjoyment and pleasure out of her job and yet not enough that she loses very important government benefits.

That is the best of both worlds between the public and the private that come together then you are covered on all basis. But a lot of people don't know that their adult children can continue to be covered if their income earnings are low.

I didn't know that and kind of wondered what would happen when he ever gets past that age.

It is only an issue if you have group health insurance, and you do have to notify your insurance carrier within nine months of them aging off the program. You can't wait until the last minute to tell them.

**Q: Special needs trust set up to help them with their needs and then let's say gene therapy or something came along that made them basically normal, what would happen to the special needs trust?**

A: Well if the parents are still alive when the restoration occurred, and what I am referring to the restoration is that even though you still have a disability you are able to function normally and go on and have a pretty normal life. The parents of course could change their will if they chose to and leave the money outright to the person with special needs. If the parents have already died, and the trust let's say has \$100,000 - \$200,000 in it or whatever, and then 10 years after the parent died there's this wonderful cure which the trust can pay for by the way, because government benefits don't always pay for cutting edge medical treatment. So the trust pays for the cure and now the person is cured and they can work. Unfortunately you cannot put a restoration clause in a trust, you cannot say if the person is disabled the money is protected and they cannot get at it, but if they are ever cured they can have the money outright. Because that is considered against public policy it's sort of an insult to the taxpayer. So I am afraid it would have to stay in the trust, but that's not bad because if you suddenly been cured and go out and work and you are earning \$30,000-\$40,000 a year. How nice to have a trust that can provide you with another \$10,000-\$20,000 a year in benefits. So the trust is still there throughout the person's lifetime. They just, unfortunately, can't have control over it, but it can certainly be used to enhance welfare of your life and supplement whatever income their getting instead of supplementing their benefits.

So it could continue to pay for normal medical expenses?

It could pay for everything, if they are not getting government benefits. It could pay for medical expenses, it can pay for a housekeeper to come in so they don't have to worry about housework, if they own a home they can pay to have a landscaper to take care of the property, it can pay for maintenance costs on their home, it can pay for them to take a vacation once or twice a year, it



## AMDA Conference Call Transcript

can pay for whatever it is they need help with. So the money isn't going to be wasted. The only insult of it is the disabled person, who is now restored doesn't have control over the inheritance his parents left him/her. So they might be a little insulted by that, but that is a small price to pay to preserve eligibility for government benefits just in case.

Thanks.

Nothing's worse than and especially this current administration in Washington wants to put Medicaid in the form of block grants. If that ever happens, there will be waiting lists for Medicaid. So you can imagine how terrible it would be if a person had Medicaid and that was paying their medical bills and then Larry dies leaving that disabled child \$50,000, therefore, they lost their Medicaid and if this administration has its way and we have waiting lists for Medicaid that person is going to be in a worse off position. Because right now until once you spend your money back down under \$2,000 you go right back on Medicaid, but if we ever have waiting lists, which we're anticipating will be the situation, that person will be far worse off because if they need to wait a year or two or three before they get back on Medicaid. That \$50,000 has left them worse off. That's why these trusts, I think, are going to be even more important in the future than they are now.

### **Q: What are typical costs for establishing a trust?**

A: Well I can't say for different parts of the country, I'll tell you what our firm charges both in Massachusetts and Illinois and it gives you something to measure it by. Although, I have seen law firms charge three and four times what I charge. We charge for two wills, which is what we call nero wills, the mother and father leave everything to each other and when both parents die it goes to the kids, but the share that goes to the child with the special need. Goes to a stand a lone special needs trust. We charge \$1,400 for that and that includes two wills, one special needs trust and two powers of attorney to health care and property for the mother and father. What those are, are two forms that say if the parents are ever incompetant they designate someone they trust to be in charge of their affairs. I am a firm believer that everyone should have powers of attorney. So for the \$1,400. Now if they are lucky enough to have the state tax problem it is more expensive than that. Seeing as that most people don't have the state tax problem that is why I quoted the \$1,400. Most law firms if the family doesn't have the whole thing will let them go on a budget plan of some kind so they can pay it off. I have some people paying me as little as \$75 a month and that's all they can afford. You just do it and put it aside when they finish paying for it then you mail it to them. And that way, God forbid, in the mean time if they die, they haven't died without a will and a trust it's done. But you can compare that to local of that \$1,400 the special needs trust is \$800, so it is basically \$600 for the two will and the powers of attorney for health care and property.

Are all of your children up there like teenagers or are they all over the place in age?

I don't have any children. I guess I am a special needs child because I am 34. Ok anyone who is over the age of 18, everyone should have a power of attorney because none of knows what tomorrow's going to bring and if we should be unconscious or unable to handle our affairs. It



## AMDA Conference Call Transcript

is good to designate someone that we have confidence in that we trust to manage our affairs to make health care decisions for us, to manage our funds for us. And if you just sign a power of attorney, then whoever you pick has that power. If you should become ill and there is no one there to sign. Someone has to become your guardian and that can be very expensive and very intrusive. Along with wills and special needs trusts I always recommend to people that the do powers of attorney as well. It's just an alternative to guardianship you will never need a guardianship if you have a power of attorney.

**Q: I don't get SSI, but I qualify for it. If my parents died and left me and left me a lot of money, that would cause me a problems right?**

A: Right so you should talk to your parents about leaving a special needs trust for you and that way you get the best of both worlds. What the government gives us is minimal and frankly we can't expect the taxpayers to give high quality of care. All they are required to give by law is give us is a subsistence level of care. Nobody wants to subsist, if you can you want to have a higher quality of life and that's the beauty of the special needs trust. It basically allows our parents to provide for us just like they do while they are alive. You know how parents can help you out a lot while they are alive they just dip into their pocket and do it. Well, when they are dead they can leave a special needs trust to do the same thing.

That makes sense.

So it's a nice way of parents providing for their children from the grave. I always tell people that I am a control freak I like idea of my money doing what I want it to do after I have died. It gives me some control over my money even long after I am gone.

**Q: Special needs trust can be set up for people long after people over 18 years of age?**

A: You can set up a special needs trust for anyone regardless of their age. I trust stuff when Jennifer, my daughter is now 37, but I set up her trust when she was only 9 . Because I didn't know when I was going to die and fortunately I haven't needed it yet, but it is there. Our life insurance policy, our pension everything flows into the trust. Jennifer personally gets nothing, but the trust gets everything and that allows her to live independently. Right now she lives in a home of her own that we bought for her and when we die the home that we bought for her will be owned by the special needs trust. So she will continue to be able to live in that home rent free plus the trust will pay all the taxes on the home, maintenance home, it will pay for her to have extras, a car, insurance on the care, maintenance on the car, whatever she needs the trust will pay for it.



## AMDA Conference Call Transcript

**Q: If she had a Great aunt or something, who left her money could she leave that money to the trust you've established or would she have to make her own?**

A: No you can't take your own money and put it into a third party special needs trust. Ordinarily if it is left to the person that needs government benefits, they'll lose their government benefits, but there is that special type of special needs trust I mentioned earlier. The qualified one that you can take your money and put it into, but when you die the state gets every penny. It doesn't go to your wife or your children or where you want it to go.

**Q: I wondered if there were two benefactors or let's say a mother and father divorced and were separately leaving things to the special needs person?**

A: They could leave it to the same trust if they wanted to. What they shouldn't do is leave it to the disabled individual because he or she can't turn around and plunk it into the trust.

But once this trust is established it is an entity?

Think of it as an empty cookie jar waiting for the cookie.

Like all your relatives if you let them know, could leave, if they were going to leave you anything could leave it to the trust instead.

That way you get the best of both worlds because you can get the SSI and Medicaid or whatever you are entitled to and then afterward after your parents died. That trust is funded and then you can go to the trustee of trust and say hey my refrigerator worn out and I need a new refrigerator or my television needs replacing or I need a new car or my car needs new tires and I don't have the money to pay for it.

And you don't have to be rich. I have a client who has less than \$30,000 in a trust that was left to her by her parents. That's all her parents had to leave her was \$30,000 and what it does is she lives on SSI, Medicaid, and Medicare and what we do is pay her train pass every month which cost \$80 and we pay her cable tv and that's all we pay. But it allows her to not worry about how she's going to have enough money to pay for a train pass and cable TV would be a luxury that she wouldn't be able to afford otherwise. So you don't have to be rich to do a special needs trust. \$30,000 to leave your child isn't exactly a rich parent, but most of us have that much to leave our children when we die, because even if you sell a house full of furniture and a car, you can usually leave your child \$30,000. People shouldn't think these trusts are for rich people because they are not.

**Q: You talked about the \$1,400 to establish the trust and things. How much is it for an ongoing maintenance? Is it the law firm that is the trustee or do you designate someone?**

A: It depends if the family has somebody that they trust and confidence in, the other family members should be the trustee. It could be an Aunt or Uncle, Brother or sister there's lots of



## AMDA Conference Call Transcript

non-profit agencies across the country who will serve as trustees for special needs trusts.

So any costs that would be associated would determine who the trustee then. The cost obviously if you are going to have a lawyer or a bank be the trustee, you need at least a quarter of a million to make it worth while, but if you are talking about a family of siblings being a trustee. I even have some cases where adult children of the disabled person is the trustee. I even have some individuals with physical disabilities who have adult children, they might be in their 50's and 60's and they have 30 year old children. So their children would be the trustee of their parent's trust. So there is no one person that can serve as a trustee anyone who is good with money and is trustworthy that's what you need, they can be trustee. It is no different than balancing a checkbook I mean you do have to follow a few other rules you have the wear with all to balance a checkbook you can be taught to be a trustee.

**Q: As I understand it the parents establish this trust for their child, they could say in their will that if this child passes it can go to the other children or charity. And if the beneficiary out lives the parents and there are no other children, where happen to the money in the trust?**

A: A properly written trust will always have a remainder mand, in other words, it will always say if it doesn't say then you will have to look at your state law. And most state law say then it goes to the heirs at law of the settler and not the beneficiary. Some people can leave the beneficiary what we call a limited power appointment to say where the money goes. The reason the limited power of appointment is important is that you don't want a general power of appointment because a general power of appointment the state will say if you can say it can go anywhere then you have to say it comes back to the state if we are helping you. If you do give the beneficiary the power to say where it goes, limit it so that it doesn't go back to the state, remainder mand is just a legal term that says where the money goes if the disabled person dies.

**Q: What states do you all live in are you all over the place?**

A: I live in Iowa, Virginia, Texas, anywhere else.

Iowa has some wonderful programs and Iowa pays for programs very differently. They have a county system for paying so you want to be sure that you whatever special needs trust you write conforms to the county rules as well as the federal and state rules.

Virginia has some non-profit agencies that will serve as trustees of the special needs trust so if you didn't have a family member you could turn to some non-profits. I think the arch serves as trustee.

Texas there are several good lawyers that do these things so if you didn't know somebody out there I could refer you to one.