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Changing the lives of people with disabilities

Kessler Foundation Podcast Transcript: Financial Tool to Enhance Quality of Life After SCI

Recorded November 2019. [Listen to it here].

HENRY STIFEL: 00:06	[music] Special needs trust. These are a legal entity that are created to help a beneficiary with special needs that help supplement - not replace, but supplement - the governmental benefits.
ANNOUNCER: 00:18	Special needs trusts, a financial tool to enhance quality of life after SCI. Welcome to a 2019 Kessler Foundation Spinal Cord Injury Grand Rounds podcast featuring wealth advisors from the New City offices of Morgan Stanley private wealth management, RBC Trust from Wilmington, Delaware and the Begley Law Group from Moorestown, New Jersey. This podcast was hosted by the Northern New Jersey Spinal Cord Injury System, which is supported by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research. NIDILRR grant number 90SI5026. NIDILRR is a center within the Administration for Community Living, Department of Health and Human Services. This presentation was recorded by Rob Gerth, Director of Communications for Kessler Foundation, and was produced and edited by Joan Banks-Smith, Creative Producer, also from Kessler Foundation, on Thursday, November 21st, 2019, at the Kessler Institute for Rehabilitation conference center, West Orange, New Jersey. Be sure and check out all of our SCI Grand Rounds podcasts. Look for the link listed in the program notes. Listen in as Dr. Jeanne Zanca, Senior Research Scientist at Kessler Foundation welcomes our guest moderator Henry Stifel of Morgan Stanley.
JEANNE ZANCA: 01:45	Mr. Stifle is a Senior Vice President and Wealth Advisor for Private Wealth Management at Morgan Stanley and a certified financial analyst. In addition to the extensive expertise in finance that he brings to us today, I wish to give credit to the efforts that he and his family have made as tremendous advocates for the spinal cord injury community. So as some of you may know, but many may not after Henry sustained his injury in the early 1980s, he and his family established a foundation, and that foundation collaborated with what was then the American Paralysis Foundation and then later on with a foundation established by Christopher and Dana Reeve to create what is now the Christopher and Dana Reeve Foundation. Which as most of us know, is a tremendous resource that we go to on a nearly daily basis to assist the people with SCI whom we serve and also serves as a wonderful resource for others in the paralysis community. We've been fortunate to benefit from Henry's advice over the years as a member of our community advisory board for the Northern New Jersey Spinal Cord Injury System, and I'm so grateful that he brought this topic to our attention today and has put together such a wonderful panel of guests to speak with you about it. And so with that, I'm very pleased to welcome first our moderator, Mr. Henry Stifel.
STIFEL: 02:58	Thank you all for being here today to discuss a very important topic, estate planning for families and individuals with disabilities. As Jeanne mentioned, my name's Henry Stifel. As many of you know I've been with Morgan Stanley for about 30 years and have been a wealth advisor for about the past 20 years in our private banking area. I also have been in a wheelchair for the past 37 years as a result of a spinal cord injury and have been on the board of the Christopher and Dana Reeve Foundation for almost that length of time. By default, like all of you, I have many friends and

relationships with individuals with disabilities and their families. The only difference is that many of them come to me to discuss their financial uncertainties that have been caused by the life-changing events that they've gone through. As you know, those stories could be complicated, devastating, and become overwhelming very quickly. My partner who's with me today Chris Daifotis and our firm have recognized that need and have done their best to create a number of both internal and external resources to assist families and individuals with disabilities.

STIFEL: 04:25

Two such specialists that we would reach out to have joined us today. Ethan Ordog, who's a partner with Begley Law Group and is a lawyer who focuses on and concentrates on estate and trust litigation, estate and trust administration, and guardianship. He's a member of the Special Needs Alliance, which is a network of highly specialized lawyers who are dedicated to serving families of persons with disabilities. Ethan's going to be doing a much deeper dive into estate planning for people with disabilities as well as some of the structures that could be utilized to secure the governmental benefits and other resources that are invaluable to people with disabilities after an injury. Also joining us in Nancy Geren, who's a Senior Vice President and Senior Manager for the special needs relationships at RBC Trust. Nancy's going to be discussing with us, the role and the importance of a corporate trustee and the necessary proper oversight for the disbursement of cash and monies from these type of vehicles and staying in the spirit of the trust.

STIFEL: 05:55

Before we dive right into it, I kind of wanted to start at, at some point in our all of our lives, all of you, no matter the size of your estate or your current health condition, we'll all probably seek counsel from such specialists as a state attorney. Maybe a wealth advisor. An accountant. You're going to be seeking advice to help out with the basic documents and exercises that we all should be doing on a regular basis and updating in order to be able to express our desires during unpredictable health circumstances that we may face. These documents, that I'm referring to, the majority of us are aware of us, but many of us don't have them in place. It's your basic will, your health care proxy, your Power of Attorney, a living will, possible trusts for asset transfer. These all help to express our wishes, maintain control, and provide proper oversight in case ever any of you are confronted with an incapacitating or life-threatening situation. In addition to these type of documents, proper exercises like--go to the next there. Proper exercises like an annual budget, a personal balance sheet, determining what your short and long-term financial goals all can be eventually married into what hopefully would be an investment portfolio to help you reach some of these goals. This type of planning is prudent for anyone. All of these documents and all your planning need to be revisited, revised, and updated. As we all know, a situation like this can have a tremendous financial impact on a family and a individual.

STIFEL: 08:00

Well, as many of us know after sustaining an injury benefits such as SSI or SSDI, Medicare or Medicaid, can all help to create some degree of financial balance and opportunities for people with disabilities. But all of them come with their own restrictive eligibility requirements. Today, we're going to discuss some of these structures to consider in order to help qualify and maintain these eligibilities. Both Ethan and Nancy are going to do a deeper dive into all of them. But as a quick introduction, essentially special needs trusts. These are a legal entity that are created

	to help a beneficiary with special needs to help supplement - not replace, but supplement - the governmental benefits. The benefits we just discussed. Special needs trusts come in many different forms. First-party, third-party, pooled. First-party special needs trusts are a type of entity, a legal entity, which can become a financial account to hold assets that are funded by the first person. The individual. That may come from an inheritance or a legal settlement as a result of the spinal cord injury. Third-party, just that. Come from third-party individuals. Your community wants to support you and help to assist with your medical expenses and supplement those governmental benefits. And then in 2014, the government created a new form of an account called an ABLE account. Stands for A Better Living Experience. These are state-ran programs very similar to a college savings plan. A 529 plan. And, in fact, an ABLE account is a 529 plan. But it too has restrictions on how one can qualify to open up an ABLE account, and there's financial restrictions on how much money can be in that account, and we'll discuss this further.
STIFEL: 10:31	So I mentioned there's that basic advisory team that all of us sometime in our lives are most likely going to seek advice from will expand in a situation like this. Your estate planning attorney needs to be a specialist in elder law and structures such as special needs trusts and they need to understand most importantly the state-specific rules centered around Medicaid, SSDI, SSI, and Medicare, in general. Of course, you're going to have a medical team and your social worker working with the family. And just as important, most likely a family and/or corporate trustee who's going to help to oversee these type of legal entities to make sure that they are being managed in a proper way that's not going to violate any of the state laws which could effect the individuals' benefits. All of this can be very complicated and it can be very overwhelming. And it's always very important to seek proper advice. Don't hurry through any of these situations. Take a deep breath. There's one little piece of advice. Pet your dogs and be happy. Because they're very, very important topics. So at this point, I'd like to pass it on to Ethan and Nancy to take the topic to a deeper level for us.
ETHAN ORDOG: 12:21	I, first off, want to say from the attorney level, somebody who gets to deal with a lot of these cases and deal with families and individuals with disabilities. I want to thank all of you first as medical professionals because most of our clients do not like their attorney. They did not like their financial advisor. We joke because we have the bad rep. They love the individuals they work in their rehab and their care. We hear that all the time. This is where you go are the ones who are helping us get to the position that we can deal with families and explain to them the legalities of what they need to be mindful of. So again, we appreciate all of your efforts and the work that you're doing. So we take a step back. Henry talked very briefly about an overview of a very complex topic. He did a great job of that. But we have to kind of talk about what leads us into this area of practice? What do we need to be mindful of? We respect your time today. I'm going to try to give you a number of overview points to be mindful of when you're talking to individuals or families, and also what the big-picture scope is of where we are today in both public benefits and the kind of planning that needs to be effectuated.

ORDOG: 13:30

So in the slide show today we're going to talk about, for anyone in the country estate planning to be effective, takes a lot. You have to be able to have information about your assets. What your goals are. Understanding your individual family situation. When you have an individual who has a disability or especially somebody who has a spinal cord injury who probably suffered it through an accident, sports injury-- I was reading one of the websites of all the reasons and the percentages of where spinal cord injuries come from. A lot of times, this is something that we're not expecting. So you have the family dynamic of dealing with that issue on top of the legality. There are constantly surveys done around the country that we rely upon to talk about normal individuals. 60 to 70 percent of families have no estate planning done at all. That's the baseline of where we come into this. How do individuals know they need to start doing estate planning? Typically, it's a life occurrence that makes them realize, "We need to do something." And see an attorney. See a financial advisor. Deal with all that. Or, as the common thing is, "My parents told me I need to do this." Or, "Someone at work told me they did this, and now I need to do it because I was told we need this in place."

ORDOG: 14:43

I spend a lot of time in court, and it's very unfortunate because individuals who do not plan, so often that's where we end up because there are fights over estates, there are issues that have been unresolved, or there is improper planning done that results in us having to go to court to resolve issues. It's costly, it's timely, and it puts people in court at a time where they're emotional, where they should not be in court. Court is not a fun place as much as people like to watch it on TV. Court does not take 15 minutes as it does on TV. In real life, it is a extended, lengthy process. They are backlogged. And these are very emotional things that, in a situation like this, most courtrooms that I go to have about as many people in this room sitting, listening to your case. And our clients, they don't really like that. They don't like people knowing their personal business, but it's where we often end up.

ORDOG: 15:33

The other thing that we have to be very mindful of is the transition of the support system. Henry briefly talked about the team that it takes, and we're going to talk about that a little later. But having the family involved, having everybody that you can have in your support system, know what is being a part of this and discuss it. Because no one in many cases sees an attorney but for a legal matter that usually is planning, right? You're not seeing attorneys or going to talk to attorneys on a regular basis. So a lot of times there's a big trust issue. So you have to make sure that the family understands these individuals are out to help you and protect you. They have no other interests in it other than making sure that you do things correctly.

ORDOG: 16:14

Okay. So very quickly, and Henry touched on it, but just an overview, individuals who do estate planning correctly, we call voluntary estate planning. They're doing their powers of attorney. They're doing their living wills. They're doing a will. They're doing a trust. In the past couple of years, we've had a lot of changes. Most individuals who have planning done, a lot of times it was done in 1975. They still have the same medical directive that somebody said, "You need to sign," when they were at a hospital because they had a surgery. They've made no changes. They've never discussed it again. And there's been many changes, both legally and just in the structure of the documents, that we have to be very mindful of.

ORDOG: 16:50

I'm assuming most of you know what POLST is. Everybody know what POLST is? No, you do not? Okay. I'll talk about that very quickly. A lot of things changed. [inaudible], New Jersey became a POLST state. The Practitioner Order for Life-Sustaining Treatment. The reason it was done this way is because the medical ethics board realized most individuals had DNRs and advanced directives in health care documents from many years ago, and they wanted to focus on in the moment when a decision is being made about end of life or a treatment that the individual would make a decision at that time and the physicians, the medical team, would work with them to make that decision. The problem is, in a lot of situations where those decisions are being made, principal, i.e. the patient, might not be in the best mindset to make a decision or discuss care plans. So we have to make sure that individuals have been appointed. Representatives are in place to assist us with that process. If that were the case that a decision was made, that's impacting our health, we have to make sure that we have someone who is authorized to assist in that decision, just as if it was a regular medical decision through a health care Power of Attorney.

ORDOG: 18:00

The other thing that really-- and this affects more and more individuals and we have to be very mindful of this, is guardianship. We're going to talk about it in a minute, but if we do not have proper planning in place, most individuals end up having to file for guardianship in New Jersey which has its issues, which we'll talk about in a second. So in New Jersey, we have several types of guardians. Guardians can be appointed of the person. They're making medical decisions, residential decisions, things of that nature. Or guardian of the person and property. Property meaning estate. So I have control over someone's assets, right? The nature of a Power of Attorney is a very important distinction. A Power of Attorney is a competent person giving another competent person the right to assist them. It does not give that individual legal authority to make all of your decisions. It's a common misconception. So a lot of times if an individual, let's say, is refusing care, a guardian might have to get appointed to be able to, not to say, always force care, but to make sure that the individual is receiving treatment, medication, whatever it is. A guardian has the authority to do that. Also, if there is end of life decision a lot of times, a guardian is the one who has to make that final decision or authorize if there is some kind of treatment, surgery, or a determination that an individual's care has to be placed on hospice, for example. Things like that. Individuals might not have the capacity to make that decision, hence, why guardianship has become more and more involved.

ORDOG: 19:25

New Jersey, we're in the forefront around the country. When we go to other states and we talk about guardianship a lot of the other systems are very behind what New Jersey has enacted. Because back even 10 years ago in New Jersey we either had a full guardianship or no guardianship. Those were kind of our levels. Now, because of our Chief Justice in New Jersey, Justice Rabner, he has really pushed to really try to understand limited guardianships. So maybe an individual might reserve the capacity to make certain decisions, but other decisions for their protection, we need to have a guardian in place. Then, the courts can kind of work that issue based upon the situation. So a lot of the stigma of guardianship has gone away because now we can

	limit the scope of that guardianship and make it more beneficial for everybody to make sure that protection is there. That's the key. All estate planning, guardianship, conservatorship, the way we look at in New Jersey, it's called a protective arrangement. What gets somebody protection to make sure that their interests are protected, both from a personal level, a medical level, and a financial level.
ORDOG: 20:30	New Jersey also, we're on the forefront. There's a guardianship monitoring program that has been enacted. Throughout the state, every county has their own guardianship monitoring program. They are now overseeing what the guardians are doing. They require a guardian to file annual reports, both of the person and the property. How does this impact you guys? The property is simple. You do an accounting. The person filing requirement has to include medical documentation signed by either a doctor or other medical professional indicating that individual may still have incapacitations of the cognition that does not allow them to be making their own decisions and still be in need of a guardian. So you may have somebody who comes forward and says, "Can you sign this document, I have to file this report?" And again, depending on what your role is in the care planned for an individual, you may be asked to look at that and sign a document that indicates the individual still needs a guardian because they're unable to make decisions on their own.
ORDOG: 21:33	Parents and family. For you guys being front line talking to individuals who come in, or families that are a part of it, we recognize the emotion of it. We talked about it earlier. Something has happened that's dramatic and they are all focused on trying to make sure the care is correct. One of the big things is advocacy, right? We live in a world where insurance providers don't want to cover what they used to. The level of benefits in this state continue to dwindle. So we'd be very mindful of advocating for the rights of an individual, both at the insurance level. Are there other resources that we can find to help pay for services? To help pay for costs of living? And that is a very important part. And a lot of the family takes on that role often because the individual is focused on their care. They're focused on their rehab. They're focused on whatever it may be. So we have to be very careful with making sure we have the right network advocating. Understanding a person's needs. What are their medical needs? What will they need in the future? What is their living arrangement going to be? Are they able to go home? Do we need to make modifications? And where are the resources to make those changes coming from?
ORDOG: 22:44	And, of course, the finances. And Henry made the point about the budget and Nancy, I'm sure will talk about the budget too. Budgeting is so important to make sure we know, with our resources, what can we afford? What are our limits on earning additional income that may impact other public benefits we have? So we have to be very careful with what we're discussing with individuals. Because often, there's a lot of misinformation out there. And individuals get guided by, "Well, this person told me this. This person told me this." And every situation is unique. Every person has their own set of circumstances that impact what they need and what they're eligible for. So we have to be very careful with what we're guiding individuals to go toward. For most individuals, you're not eligible for many benefits because a lot of the restrictions are until you reach 18, including social security. Some individuals can qualify for social security disability depending on their situation and how much they've worked, or if

they have a parent who is disabled or retired, they can get benefits through that individuals' work history. Guardianship in New Jersey, full guardianship cannot take place until we're 18. So if there is an individual who's a minor, most parents are guardians of the person and property. What's called - a very legal term - in loco parentis. However, if a minor child is receiving a settlement, for some reason - if you have a client who's a child who was part of an injury and now they're getting money - you do have to, as a parent, go to the court and become a guardian of the minor's property, or it gets put into a special needs trust or whatever it is, based upon what the court will direct. So it's something to be very mindful of.

ORDOG: 24:20

The other thing that so many of our families are finally really starting to look to are what we call life care plans. Now, in litigation, and I don't want to bore you with litigation, but litigation you have a plaintiff and a defendant. Somebody did something to somebody who's now suing them for damages, right? As you can imagine, the plaintiff's life care plan says the person's going to live for a very long time and need a lot of money. The defendant, their life care plan says the person's going to live a year and spend $10, right? So we need to get a independent life care plan in a lot of situations that is used as a resource. What is the person really going to need with their set of circumstances, their injury, their availability of public benefits and resources of how much money it's actually going to cost? Because we are only as good as knowing if I have $1 million in a pot for a trust, how much we can spend for different services or different equipment and where we need to find other resources to try to cover those costs. This is why it's so important to make sure that we understand what that individual's needs will be because it impacts everything, okay?

ORDOG: 25:37

Next slide. The final considerations, very briefly. We won't spend much time on this. But again, cost of services. What are health care options? It's tough in the legal market because with different changes in political leadership, there are different focuses on health care where certain policies and certain regulations are more beneficial to us and others are more restrictive. So it's hard as a lawyer because we often talk to individuals about what benefits they're eligible for, but it's an ever-changing process we have to be very mindful of. Public benefits and eligibility. Again, a very tough situation because it's so fact-specific. For most individuals, they're limited in what they can qualify for. Or depending on their disability or what has happened to them, what additional resources are out there. A lot of individuals do not know what resources are out there. So it's so important to make sure that you are discussing and seeking out professionals who can guide them through that process.

ORDOG: 26:39

Next slide. So very quickly, and I put this slide in here, and it's just very important because social security over the years has become a much more thorough reviewer of the medical condition before somebody's going to be eligible for social security benefits. I simply just include the definition of disability because it is what the individuals who are making this determination rely upon, right? So when we are looking at a disability, it's an inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment. And technically, it's supposed to be with us for a continuous period of not less than 12 months. So individuals, especially in the rehab world where you have a patient who's come in who may be eligible because of their present situation for either temporary or long-

	term disability, they have to be very mindful of, as my condition improves and I might be able to go back to work, that I have to be notifying social security that I might not always be eligible for the same benefits. It may be a continuation, but it may change a little bit. Not telling - which is what people come to us and say, "Well, I just didn't tell social security that I'm working again - that is a problem because you're committing fraud, right? So already when you're dealing with a lot of emotional issues, physical issues, and legal issues, you now have to make sure that you're mindful of in explaining to people, "Just because you were eligible before it may have changed now."
ORDOG: 28:12	Some of this general diagnosis, we'll kind of skipped through, but this is kind of a list of what social security recognizes as disabilities as defined. Even 15 years ago this list only had about 5 or 6 items on it. It now has about 30 that social security recognizes as actual disabilities. Legal documents, again very quickly. [The parents, the individual disability, have the same documents, wills, Power of Attorney, etc.?]. One of the biggest issues that we have really talked a lot with individuals and parents about over the past few years is the bottom one. Letter of Intent. We talked about the family, and getting everybody involved. The individual, a lot of times, will tell us, "We don't really feel as though we're in control of our lives anymore because of a disability that has occurred major accident. We're relying upon other individuals for things that we once did ourselves." They have taken great pride in writing their Letter of Intent of where I see my life going. What are things I want to accomplish. Because I want to make sure the individuals who are helping me, understand this. That my family understands that I may have this issue, but I'm going to overcome this or my goal is this.
ORDOG: 29:23	And similarly for the parents. Maybe the child with a disability may not be able to do everything they once thought they could do. It's also very important that the parents have the ability to sometimes write Letters of Intent to explain when we're gone, what is the goal for the individual. What have we done. Who are the doctors we've seen. Just give an overview. Because so often they're the ones who are the boots on the ground and family just hear about it. Now, sometimes family has to undertake the task of resolving issues that they were not asked to do before. So our clients have really enjoyed the opportunity to write and understand what the issue is that they're dealing with.
NANCY GUERIN: 30:01	Yeah. I'll add one thing. In the folders that I have upfront, I have a guideline for a Letter of Intent. So I work for a corporate trustee, and often times we are coming on to a trust. Maybe parents are deceased. So there's a special needs child or a special needs adult that we're working with. And that Letter of Intent is so valuable to us as a corporate trustee because it really explains the personal, intimate details of the disabled individual and their parents' wishes' for them. So if you want to grab one of those whenever you leave I think it's a great guide for families, even if they don't have some type of trust structure, but just to have that Letter of Intent on file.
STIFEL: 30:46	Nancy's going to talk in a few minutes about her overview of special needs trust from the corporate trustee perspective.

GUERIN: 30:52

Right. So I'm sure most of you, or all of you have heard of a special needs trust, correct? Hopefully so. So the purpose of a special needs trust is to take assets out of an individual's estate and allow them to qualify for certain types of government benefits. The main ones that you'll hear about in your daily life is Medicaid and SSI. So a person cannot qualify for Medicaid or SSI unless they have less than $2,000 in their name, 1 home, a car, and then there's a few other miscellaneous things. So for a lot of your patients, once they sustain a spinal cord injury funds can really be depleted very quickly. And the remaining funds that they have or if they win a settlement, it might be very important to put those funds into a special needs trust so that they can qualify for those Medicaid benefits and SSI. A special needs trust also is a protection vehicle as well. So it does offer a certain level of protection from creditors' claims to that beneficiary.

ORDOG: 32:03

So very quickly, and one of the, again, misconceptions is, and in New Jersey, we, unfortunately, have this problem a lot, are the distinction between first and third-party trusts. So first-party trusts are the assets of the individual. So as Henry said earlier, usually, it comes from a legal settlement, inheritance improper planning. One of the big issues that occurs in a lot of these situations, families plan but they don't plan for everything. And they have a life insurance policy at work. They've done all the best planning in the world, but they forgot to change the beneficiary of that policy, and money comes to individual on benefits, and we've to go to court to fix that. First-party money, the trust sits there. As Henry said earlier, the federal standard is the trust is there to supplement rather than supplant public benefits. If you take nothing else out of what a family asks, "Why do I need a special needs trust?" That is why. It is designed to maintain the benefits without having to basically use all the money that you've either inherited or received in a settlement. The reason first-party trusts everybody says, "We don't want a first-party trust, we want a third-party trust," but you really can't always do that - is because Medicaid and other individuals that potentially have lenable interest. So they've given us benefits. They have a lean against me because I've received services - when I pass away, they're entitled to a payback from the trust.

ORDOG: 33:31

So let's just say there's $5 million in a trust, and during my life, I have $2.5 million dollars of services through Medicaid - for rehab, for costs of care, a residential placement, whatever it is - Medicaid gets the first handout of distribution. So they get their 2.5 million. Where does the other money go? Well, it depends. If the individual's competent, they can elect where the rest of the money goes. So family, charity, friends, whoever it may be. If there's $5 million the trust and Medicaid's lean is $7 million, Medicaid gets $5 million and that's the end of it. There's no further claim because that's all that the individual has for an estate recovery claim. As opposed to the third-party special needs trust. A third-party special needs trust is developed by parent, grandparent, other friend, family. Those assets that are in that trust, similar protection for public benefits, but there is no payback provision. So if parents establish a third-party trust and do appropriate planning and direct all of their assets to a third-party trust, Medicaid can still be there. They can provide $5 million of care, the trust could have $1 million in it, and when the individual passes away, there is zero dollars owed from that trust for public benefits.

ORDOG: 34:54

The mistake people make is twofold. Some of them have trusts that say they're for the benefit of an individual with a disability or special needs. There are very specific provisions that have to be in these documents. So individuals that just have a general support trust and it says, "I have a trust. Income principle can go to the beneficiary," that is not a protective avenue for somebody who has a disability or could potentially qualify for governmental benefits. Because if that money can be used for them, Medicaid says, social security says, "Why do you need us? That trust can make the payments." So the trusts have to be somewhat restrictive in nature. Subject to what we're allowed to utilize those funds for, which we're going to talk about in one second. So very quickly, this is more of making sure that we're talking about the logistics. The distributions have to be discretionary for the trustee. Where do funds go at death? A lot of individuals in the third-party world, parents, they establish it now, but it's not funded until after they pass away. Either through life insurance or their estate, right? Because if we establish the trust and fund it now, we have to file tax returns. Deal with those types of issues that otherwise do not come up if we do not fund it to after we pass away. Doesn't mean you can't fund it during your lifetime, but most individuals, like I said, fund it through life insurance, retirement accounts, things that are passing when they are no longer with us.

GUERIN: 36:23

So Ethan touched on distributions. One of my biggest jobs as a corporate trustee is making sure that distributions are made appropriately from a special needs trust. They've both touched on it that really a special needs trust is there to what's called supplant, or sorry, supplement and not supplant government benefits. So Medicaid may provide rehab. Medicaid may provide caregivers that come into the home. It may provide medications and things like that. The trust is there to supplement that Medicaid benefit. So the trust can pay for a handicap modified vehicle. It can purchase a home. Well, depending on state-dependent, it can pay for rent in some circumstances. Education. Hobbies of the beneficiary. For them to take trips to go on vacation. Personal hygiene items and things like that. So there's a lot of things that the trust can cover while still maintaining those Medicaid and SSI benefits which are very important to someone with a TBI or a spinal cord injury. We often get questions I think before a client actually even gets to Ethan. And the big question is, when do we fund a special needs trust, ow do we fund a special needs trust, and what assets do you use to fund it? There are two ways that you can fund. You can either create a trust during your lifetime, or you can create a trust under your last will and testament. It really is all situational. It depends on the needs of the beneficiary now versus later as to when you fund it. Most people use cash, life insurance, IRAs, and sometimes real estate to fund special needs trust.

ORDOG: 38:21

So again, and this is a situation of public benefits, if somebody's getting SSI and Medicaid, they're going to need a special needs trust to protect those benefits. If someone's on SSD and Medicare technically since those programs are not income and resourced, basically, based you do not need a special needs trust at that time. However, this is the cautionary tale. A lot of individuals, especially as we transition, and get older and maybe need additional benefits, a lot of individuals get on what's called either a Medicaid waiver or some other form of Medicaid that might be available to them, that they do need a trust even though they are on Medicare SSD. A lot of individuals qualify for SNAP. You definitely need it for that. And the big thing too, that a lot more of individuals are getting eligible for because there's more of it, and that's Section 8 housing. If you are getting subsidized housing, you also need to be Medicaid eligible to qualify for that program. So if you're receiving SSDI Medicare, but somehow you qualify for Section 8, you still have to have a trust to be able to not have your assets be countable. So it's very important. That some individuals are on SSD and Medicare and people say, "Well, they don't need a trust then. That man told us at that seminar, they don't need a trust." That's not always the case because there's other eligibility potentials for other programs.

ORDOG: 39:44

So very quickly, one of the things we talked about on our conference call was returning to work and things of that nature. So there are many programs in assistance that concern about eligibility to maintain benefits is paramount for many individuals, because even though they might go back into the workforce, they still need to rely upon insurance or some other source of benefits to cover and supplement their lives. So the regulations now, which will change in 2020, a single individual can earn $771 a month in other income and not lose their benefits. And if you're married, it's $1,157 now. Now, that is not a straight number. There are other exceptions to that rule. Some things are not viewed as income. Some things are able to be deducted before they actually find it as countable. But it's not a ton of money. So it's very important that individuals realize, "If I'm going back to work and I'm getting a $40,000 a year job, I might not longer be eligible for their benefit. So I have to make sure that I have private insurance in place. That I'm thinking this all through."

ORDOG: 40:49

Because it is very tough. We have a client who comes in and says, "I sustained this injury. I'm now ready to go back to work." And we have to tell them, "Well, what insurance are you going to be covered by? When is this going to happen? Because you're still dealing with physical therapy. You're still dealing with this." And I don't want to be the bearer of bad news a lot of times, but we have to work the issue. We have to not want to bring somebody down from the high that now they're doing this. And this why it's so important to make sure you have the professionals in place. One very thing on that slide, it's not enough to go back to it, is there are now specialized life coaches who are dealing with the disability community who are basically discussing how to transition back after being away from working or working it with now maybe limitations that you might have or otherwise. And a lot of our clients are now talking about the need to have a life coach. Because their family is obviously very supportive. They're saying, "You can do it. You can do it." But they're like, "Can I? I'm not sure. I need somebody else to be there, who's independent who's also pushing me in a positive direction."

GUERIN: 41:51

And I'll just add, New York and New Jersey both have really great programs right now for the life coach. I have clients in both states that have used life coaches that have helped them reintegrate into society. Whether it's finding a job or finding community centers. Finding people who can share in their experiences. So we touched on funding. I won't talk about that. But just very quickly, I do want to talk about ongoing investment management. When you do have a trust, it's very important that those assets be invested appropriately because that trust really needs to be there for that beneficiary for as long as possible and hopefully for their lifetime. So it's important that you have a balanced approach to your investments. Not too risky. And also, that you have a budget for the trust as well so that you know the liquidity needs of the client. The cash needs. All very important when you're discussing investments.

ORDOG: 43:00

And I just want to make one quick point about that, and this is the hardest part, I think, that we have to deal with it all. When there's an injury or a settlement and someone has sustained an injury that now results in special needs trust, the family all thinks it's family money. It is not. That money is for the benefit of the individual who has been injured. And unfortunately, again we're always the bad ones telling them, "This is not family money. You can't now all live off the trust." Because that's what sometimes individuals will think they can do, right? $5 million sounds like a great number. When you're 35 years old and have sustained an injury, that $5 million with your care costs and needs the rest of your life is not much money. So it's very important that we set reasonable expectations with families and say, "The budget can't be that you're buying a new Maserati every year because that's what you want." It has to be that it's within focus of what your needs are and what we can help the family with, but not always give them direct money. So the trustee, and Nancy, we love her. She's a wonderful person because she cares very much. And the reason I've enjoyed every time we get to interact is because I learn something from her every time because they're in a hard position because you have so many individuals who want to question what they do, that that's why it's so important to make sure that you have corporate individuals and individuals who know public benefits.Understanding what's in the best interest of the beneficiary and not giving into the family saying, "Please give us all $50,000 a month out of the trust." You just can't do it.

ORDOG: 44:29

Investment expertise and finding the right people who can assist with the management of the investments. Making sure that we are not invested in things that are too risky because we need the longevity of the trust. Understanding taxes. Filing returns. Keep records. This is one thing that we often debate with families. "Well, why can't our son be the trustee?" Well, do they know--?" We pull this list out a lot. We show it to them. "Do they know all these things?" And, of course, the family says, "I don't know. I mean, my son does this or that. I don't think he keeps a checkbook for himself." That's not somebody who you want to manage a $5 million-plus trust when it's a disabled individual. When I talk about people pointing their finger, you have social security, you have Medicaid all questioning all the distributions. In 2017, there are these regulations that are federally based of what can and cannot be done with funds from a trust. They change four times in a calendar year. Individuals who are making distributions that were right on a Monday, on Tuesday found out you couldn't do that anymore. And of course, they had made a bunch of distributions. People lost benefits because of it. That's why it's so important to have professionals who understand the logistics of distribution. You can go on [laughter]. So the ideal trustee, we talk about the professional who will work with a family member, right? So it's not that we're saying, "Nancy's now the trustee and you're never going to talk to her again. The families out of it." They meet with and speak with the family. They sit with the individual. And then everybody develops what the expectation is of the trust. What the needs are for the individual.

GUERIN: 46:06	So on that same note, kind of carrying with that, people often ask me whenever I'm speaking with families when they're in the planning stages, "Should we appoint our son as the trustee? Should we appoint a family member as the trustee?" And I kind of go through the things that Ethan just went through. I mean, I think it's very important to understand public benefits. Do they know the ins and outs of public benefits? Are they going to keep statements? Are they going to file tax returns? What happens when they die? What happens when they become incapacitated? What happens when sister comes to brother and asks for a distribution and really tugs on the heartstrings? I mean, I think putting an individual, especially a family member in place as an individual trustee is a difficult position to put them into. A corporate trustee has many advantages, most which are listed here and what we've talked about. I mean, we have many years of experience in our trust company. We are able to be impartial. We are able to be objective. We are able to answer Medicaid whenever they send a letter and ask for documentation on all of the distributions out of the trust this past year. So there's a lot of things that I think family members think that they can handle, but once they really get into the weeds, they realize that they're in over their heads and a corporate or professional trustee is probably more well-suited for the job.
ORDOG: 47:44	And the other thing that comes up in so many of these cases is, we love the personal injury attorneys, especially the ones who get these large settlements. But they tell the families a lot of times, they'll tell them, "Well, you can now buy this house, this car, this whatever." And again, we have to explain to them, "That's true, to a degree, but we have to be mindful of how this plays into our situation." The other thing that they always tell them is, "This settlement is not taxable." So they're like, "That's great. Okay. All this money is not taxable." But once the money's invested and grows, you still pay income tax just as anybody else. And they'll question the trustee and say, "Why are you filing income tax returns?" "My attorney told me this is not taxable." And it's like, "Well, right. The settlement is not taxable. Once you invest it, we have to file tax returns and pay taxes just as if anybody else had made money, so." The other thing that we do a lot of, and this is the initial part of what we talked about with the family, and to Henry's point earlier, we usually have a counseling session with the family and we bring everybody together. We have the individual with disabilities, family members, a trustee, you have your attorney. We talk about immediate cash needs. What are the things that need to happen now?
ORDOG: 48:47	And a lot of times we'll look to that life care plan we talked about earlier. What are things that may be a 1-year issue, a 5-year issue, a 20-year issue? Because we have to make sure that if we're going to spend a bunch of money up front that we know that the investment return will be enough to cover things that we're going to need when an individual in their-- in 20 years from now we know that we're going to need a new van. We're going to need a new state of the art wheelchair. We're going to need a ramp. We're going to have to deal with all these things because we cannot always be reliant upon public benefits or the coverage under insurance to get this equipment, especially where we're going now. We keep hearing that there's not funding for these things. It's only going to get worse. So that's why if there is a pot of money, as great as that is, we have to be so mindful of what we're doing with it now and having it available in the future. Managing expectations is probably the biggest part of what we

as attorneys do. Because we have to be the reasonable, rational mind of, "You have to do all these things legally. There's a lot of people who are going to question what you're doing with this money. So we have to be very sure that we have the expectation of what this money is there for and how it's going to be used."

ORDOG: 49:57

So again, we can probably skip this. We've talked about our whole team of individuals. So very quickly, Nancy talked earlier about Medicaid qualification. So you have to be below $2,000 to qualify for Medicaid. A lot of individuals that have assets, there are ways to spend money down. Getting a pre-paid funeral. Certain expenditures for the individual. There's ways to legally spend things down. Transfer of assets is tough. What a lot of people say to us is, "Well, you told me I have to have $2,000 or less. I'll just transfer all the money to my parents and be done with it." That's not the answer. Medicaid will say, "That is an inappropriate transfer. You're now ineligible for benefits until they give the money back and you spend it down," right? So there's apparently some website called what to do with your money to get on public benefits and apparently a lot of people blog about, "Well, if you just give it to your friend, family member--" that's not a good blog to point people to because that's incorrect.

GUERIN: 50:51

And Medicaid does have a five-year look back period in most states. So if you give that money away, they can go back five years. Look through your bank statements. And so it's a longer waiting period to get reinstated.

ORDOG: 51:04

Henry talked about pooled trusts earlier. They are on the rise because most individuals don't have the $5 million dollar case. They have the $50,000 case. So there are types of trust that are more focused upon individuals that are needing the protection, but don't have a ton of money. Again, not knowing where you guys come from and what you like to read, ABLE accounts are the new hot thing. They are still very untested. I just will put this out there. Three years ago at the Special Needs Alliance meeting, we were told that the ABLE accounts were going to take half of the Special Needs Trust cases away because everyone was going to go to ABLE accounts. That number is still, say at about 90-10. The special needs trust 90%, ABLE account is 10%. Because ABLE accounts have a lot of restrictions. You have to have your disability before the age of 26, which for a lot of individuals, is not the case. So ABLE accounts might not be available to them or they might not have eligibility. You can only contribute at this juncture $15,000 a year. So if somebody gets $1 million settlement they say, "We're going to put into an ABLE account." You can't do that. So this is very important to be mindful of.

ORDOG: 52:12

When, in my opinion, has the ABLE account helped us? Special needs trusts are limited in their ability to pay for shelter. So residential apartment settings, etc. If an individual only received $1,200 a month in SSD, you find me the apartment that only costs $1,200 that's nice enough to live in. If there are funds in the ABLE account, the funds in the ABLE account can be used to supplement your rent without it being viewed as income to the disabled individual. That's where individuals are using the ABLE accounts now to help with housing. That really is the big crux of where we're seeing ABLE accounts used. Several of the states that passed their ABLE accounts are now back in their legislative branch because they didn't include provisions that they

	needed to. So some states their ABLE accounts right now are on suspension almost because they're not valid. So if individuals come to you and say, "We're not doing any planning. We're only going to rely upon the ABLE account," just be careful with that because there's a lot that's really not a positive in it right now. You don't have to look at this slide. That was just our thank you. That's a common one. But we like to open up to any questions and answers. I know that's a lot of information in a very short period of time. I just did this presentation without Nancy's wonderful slides a couple weeks ago, it was a three-hour presentation, and I was cramming it in there. So we recognize we have put a lot of stuff in a very quick period of time. So does anybody have any questions? Okay.
GUERIN: 53:40	I just want to say--
ORDOG: 53:40	Oh, yeah, a question. Yes?
AUDIENCE: 53:42	[I have a question]. Going into kind of the limits on how much somebody can earn once they go back and it starts to disqualify them from benefits and things like that, would a contribution to an ABLE account-- so if I took part of my income each month and deposited that into my ABLE account, would that be deductible?
ORDOG: 54:05	So [laughter]--
AUDIENCE: 54:06	Let me add to that, so then you can answer each one. Or let's say I've got a job, but I live in Jersey. I mean, you're cruising across bridges or tolls, traveling distances. And its mileage, its toll charges. You may have to pay to park your car in a safe place. Are those things considered business or work-related expenses?
ORDOG: 54:31	Correct. So let's take the first question first. Individuals can put funds into an ABLE account. Now, each state, depending on where you're ABLE account is-- so a lot of individuals who live in New Jersey, for example, don't have a New Jersey ABLE account. They have an account in Ohio, or they have an account in North Carolina, or they have an account elsewhere.
AUDIENCE: 54:49	[crosstalk].
ORDOG: 54:49	What's that?
AUDIENCE: 54:50	Pennsylvania.
ORDOG: 54:50	And the Pennsylvanian one is one of the ones that's technically invalid right now because there's no payback put in it, so they're revisiting it. But individuals can contribute. Actually, in Pennsylvania, there's a commercial that shows a firefighter, and he's talking about how he utilizes his ABLE account to maintain his benefits and put funds in there. So depending on the state, you can contribute. To your second point about travel expenses and those sort of things, under our earned income, there are deductions for certain expenses, including different travel things. Different medical expenses that go as a deduction from what you earn to get to your limit cap. So again, depending on what your situation is of travel or what expenditures you have, that in order to maintain that work you have to spend money on, they are not counted against you from that cap number.

AUDIENCE: 55:38	So if you were advising somebody who was considering going back to work your advice might be, document your travel, your mileage, tolls? Be religious about keeping track of these things.
ORDOG: 55:51	It's both keeping track of it-- and-- again what I talked about earlier, as much as I don't view the people on social security as being negative, they're all very nice to us. We want to have open lines of communication with them and say, "I've qualified for benefits before. I'm now going to do X, Y, and Z. Explain to me in my particular situation and what I've qualified for and all my program levels what I can make. Because here my expenses I have to pay. Here's my out-of-pocket medical that no one else is reimbursing me for that is not viewed negatively against me." And they usually are pretty good about trying to work with you as long as you get an appointment and speak to somebody. So again, it's not that-- when a lot of mistakes come in-- people will just go and Google and say, "What can I do to maintain my benefits?" And there's 60 things that come up, right? But it's not your individual case. So every person has a different situation of what eligibility requirements they have.
AUDIENCE: 56:46	And then finally, sorry to be--
ORDOG: 56:48	You're fine.
AUDIENCE: 56:50	Let's say I'm an individual who is receiving Medicaid, and I want to go back to work. And while on Medicaid, Medicaid is paying up to $50,000 each year for my medical expenses. And after my injury, or not-- after I come off that, is that 50,000 also, I mean, considered a potential deductible in the sense that that person needs to make an additional 50,000 if they were going to come off medical care?
ORDOG: 57:25	So this is to maintain Medicaid, or--
AUDIENCE: 57:28	Yeah, [crosstalk].
ORDOG: 57:28	--in opposition to Medicaid?
AUDIENCE: 57:30	No, to maintain Medicaid.
ORDOG: 57:31	So again to maintain Medicaid, this is where we're more restrictive in what we can earn and what assets we can have if we're making the switch out. That's why it's so important to make sure that we have our private insurers in place before we're doing that because they're going to very quickly say, "You're now earning money. You're no longer eligible for our services because you're able to have your own insurance, do whatever." A lot of individuals, especially when there's a trust involved or a family involved and they know they're going back to work and they're going to lose their benefits, they will get private insurance before the waiting-- some people have a 60-day waiting period and some people have a 90 day waiting period. They'll start private paying to have the insurance in place so there's not going to be any gap or lapse in coverage. Because anybody should have insurance. Someone with a disability, we really need to make sure we have insurance because we never know what's going to happen. So those are all very good questions. And if Nancy has any comments, she can jump in too.

GUERIN: 58:24	Well, I just wanted to comment on the ABLE account because it is a sticky, sticky thing. It's a great thing. It's a great piece of legislation that passed. But ABLE accounts, it is similar to a trust in that you have to keep very detailed records. If you make a withdrawal in February, that money has to be spent in February. You cannot carry it over to the next month. So there's a lot of intricacies that people need to know before they fund an ABLE account and start using an ABLE account. I do think they could be very helpful for a lot of individuals, but they are new. They haven't been tested that often in the courts or with social security. So I think we tread lightly at this point.
ORDOG: 59:09	The other thing that the ABLE accounts-- I think Henry's slides talked about it being having a debit card. We've already had situations where individuals have said to us, "Well, I have a special needs trust, but I also have an ABLE account. My special needs trustee told me I can't use the money to take my friends at dinner, but I'm using my ABLE account to do that." And I immediately put my fingers in my ears just because it's wonderful you're taking your friends out. I cannot tell you that as these get more tested that that is going to be something that somebody's not going to come back and say, "That's a direct violation of what the terms of the ABLE account are supposed to be there for," right? So this legislation has only been enacted the past couple of years. As Nancy just said, it's very untested what's going to happen with these. And as I said, once the federal law got passed the states all tried to very quickly develop their own legislation and a lot of the states that have ABLE accounts that have been approved literally have gaps in the legislation because they will wait to a later date to finish writing that portion because we want to have it in place. There's some issues. That's why the Pennsylvania one they wrote without a payback. So our friends at Medicaid who oversee the ABLE accounts that Pennsylvania have said, "Do not fund the ABLE account of Pennsylvania until we resolve this issue. Because right now if a person has an ABLE account, we're going to view it as a countable resource because there's no payback to Medicaid." So we have to be very careful with the logistics of this. So these are all very good questions. Any others?
AUDIENCE: 01:00:34	Yeah, one final one then.
ORDOG: 01:00:34	[inaudible].
AUDIENCE: 01:00:36	If they're listening on SoundCloud, and they're talking to a patient who wants to go back to work, what's step one? Who do they contact? Or a family member, who do they contact?
ORDOG: 01:00:55	So again, maybe I'm not the expert on who they contact first. I will tell you that they should-- depending on who's already involved in their situation, we will tell individuals, "A lot of the places that our clients have gotten rehab they have support groups, transitional teams that they first a lot of times will go to get underlying information. The second issue is obviously their trustee, their attorney, financial advisor to make sure that the programs I'm on right now, what do I have to do to maintain them or how much can I make, number one and number two? Number three, and this is the big point to your question earlier, if I'm leaving the Medicaid realm of insurance coverage, I better darn well be sure that we have enough money

	and I can get a provider to give me insurance before I just start my job. Because if I start my job and they say, "You are eligible to join our medical insurance coverage," that's wonderful, but normally, there's a 90 day wait period in there. So once I start earning my money, I now lost my Medicaid. What am I doing for that period of time?" So a lot of it is the forward-thinking of people. Like I said earlier, they get very excited. Like, "Well, now I can start my life again. I'm going to go back to work. I'm going to do this, I'm going to do that." But there's so much of how we have to think about going into that transition to make sure it's all working together for us as opposed to against us.
ZANCA: 01:02:17	I thank our panelists so much for their expertise today. [applause] Thank you.
ANNOUNCER: 01:02:22	For more information about Kessler Foundation, go to kesslerfoundation.org. Follow us on Facebook, Twitter, and Instagram. Listen to us on Apple Podcasts, Spotify, SoundCloud, or wherever you get your podcasts.