Planning for a loved one with special needs

Tuesday, November 30, 2021

TRANSCRIPT

PRESENTERS:

Jonathan Desautels, Moderator, Vice President, Branch Leader, Fidelity Investments
Kelly Quinlan, Vice President, Advanced Planning, Fidelity Investments
Ann Koerner, President and Founder, National Care Advisors
Ken Shulman, Of Counsel, Day Pitney LLP
Meredith Greene, Partner, Day Pitney LLP

Views expressed are as of 11/30/2021 and based on the information available at that time and may change based on market or other conditions. Please read the last page of this transcript for important additional information.

Jonathan Desautels: Well, good afternoon, and welcome to our wealth management webinar on special needs planning, including potential incapacitation. My name is Jonathan Desautels, and by way of introductions, I've been at Fidelity for 18 wonderful years. And currently I have the privilege of leading and outstanding team of financial professionals serving our clients in the Stamford, Connecticut area. I have a passion for this topic based on my own personal experiences and those of my office. Before we begin let me just cover a few housekeeping items. First, we cannot see you. You can only see us. So sit back and enjoy today's event. Second, while this is live, we cannot field any questions. We did, however, receive many questions ahead of time and thank you to those who actually took the time to ask us one. We plan on addressing many of them during today's event and during the question and answer at the end. And lastly, a number of the questions we received were specific to caregiving and eldercare. Today our topic is focused on high level special needs planning and we'll not be doing a specific deep dive in caregiving or eldercare. However, we do have information available in the life events page on Fidelity.com and we recently ran a seminar webinar on this specific topic. And based on your questions we may run additional events on that in the future. So let us begin.

Special needs is an all-encompassing term often used when planning for individuals with one or more disabilities including congenital, intellectual, developmental, or learning, resulting later in life from a potential injury, maybe medical malpractice, mental incapacitation, or any type of other special need or disability. And today we're going to talk about five key considerations and strategies as you're planning for a loved one with special needs. Number one, creating your vision for you and your family. Number two, understanding the role your family will play in that vision. Number three, the different financial strategies available to you. Number four, common questions and things to watch out for. And number five, how you can get started or take steps to improve your plan. At the end of the session we hope that you will know that number one, you are not alone. We hear from many customers, our own family and friends that this is a topic that they want and need additional help and support on. And number two, that there are resources Fidelity has available to help you navigate this type of planning need.

So to help in this discussion today Fidelity invited four panelists who bring a range of expertise. We know that this topic is complicated and that there's a lot to consider. Today they will share their perspectives through the lens of financial, legal, and quality of life considerations. They'll share their experiences and knowledge with each of you. Before we begin I've been asked to remind you that the panelists' opinion are their own and not that of Fidelity's. Also keep in mind that we will be presenting information that we hope you will find informative and educational. But your situation is unique. And the panelists' suggestions will not be reflective of your personal situation or circumstance. You should always consult your own attorney or tax adviser. So Kelly, Meredith, Ken, and Ann, welcome. We're excited to have you here today. I'd like to start by just doing brief introductions rather than me reading all of your bios. So maybe we'll start with Kelly, then move to Ken, Meredith, and then lastly Ann. So Kelly, I'll turn it to you to introduce yourself.

Kelley Quinlan: Okay, great, well, thank you very much for having me. So my name is Kelly Quinlan and I'm part of Fidelity's wealth management and personal trust team. So I'm an advanced planner and I'm one of 30 that are seated regionally across the country and I cover most of New England. And our role is to sit down with our high value clients to talk about very specific issues regarding estate planning such as wills versus trusts, revocable trusts, irrevocable trusts, estate taxes, gifting. And we spend a lot of time talking with our clients about special needs trusts. So I am an attorney by background but in this role because I work for Fidelity now I'm not allowed to provide direct legal advice or to draft your documents. But our hope is that we can use these types of conversations with our clients to talk about various estate planning situations so that our clients will be better prepared when they sit down with their attorney to have a more formal discussion. And now I'm going to turn it over to Ken.

Ken Shulman: Thanks, Kelly. I'm Ken Shulman and I'm an attorney at Day Pitney in Boston. And I'm very excited to have this opportunity to share my experiences with you. Most of my career has been devoted to special needs planning, also sophisticated estate planning but with a special emphasis on the special needs area, special needs planning, trust administration, and guardianship. Day Pitney is a regional law firm that has offices that spread from the New England area all the way down to Miami Beach. And with that I'm going to turn it over to my colleague Meredith Greene.

Meredith Greene: Thanks, Ken. Hi, everyone, I'm really excited to be here with you today. Like Ken I am also a special needs planning attorney at Day Pitney. I am also the mother of a child with special needs. I have four children. My oldest son Connor is 18. He's been diagnosed with Williams syndrome. So although I was an attorney before he was born, once he was born I attended a lot of these seminars like you guys are doing, and started advocating and planning for him and after a few years realized that my passion was in this area so I turned my law practice into special needs planning and have been doing that for a number of years, so like Ken I do the special needs trusts, guardianship, government benefits advocacy, DDS advocacy, and I work up here in Boston. So over to you, Ann.

Ann Koerner: Thank you, Meredith, and thank you to everyone for putting on this wonderful presentation. My name is Ann Koerner and I'm a special needs nurse case manager and consultant. Along with all of my colleagues at National Care Advisors we provide advocacy, consulting, and problem solving services for individuals and their families with special needs. We are located throughout all 50 states, so we're very portable, so we can provide services no matter where you are. Our services include finding caregiver solutions, maximizing third party benefits, and planning for the future care and quality of life for your loved ones.

DESAUTELS: Thank you, Ann. Welcome, Kelly, Ken, Meredith, and Ann. We're excited to have you. So let's get started. Kelly, to kick us off, what are some of the common questions that you hear as a Fidelity advanced planner from our clients?

QUINLAN: Okay, great, well, thank you. So we have many types of questions from clients. But most of what we hear with regard to special needs trust planning really falls into three buckets. So number one, the first and most basic concern is quality of life. How can I best ensure the well-being and quality of life of my loved one that has a disability now, or if I become incapacitated or if I pass away? And then the second most common question is what are some things that I should be thinking about from a financial point of view and a legal point of view to help ensure that my loved one maintains this quality of life. And then last, probably the most important, is how do I get started, and when should I get started.

DESAUTELS: Thank you, Kelly, so let's start with that first point. You talked about that well-being and quality of life. And Ann, I know a lot of your work with National Care focuses on those areas. Does that question resonate with you and could you share a little bit more with the audience?

KOERNER: Oh, absolutely. I think that's the number one question we get asked, is how do we plan for the future and what happens when I'm no longer here to care for my loved one. Especially doesn't matter whether it's a child or a sibling or even a parent in some cases. So when we're getting started our first step is to help to create the vision. And so we start by discussing the timeline of important dates with the family. So if you'll notice this, the timeline, we're starting at birth and we're going up until the point where the individual with special needs is no longer with us and passes on. Hopefully everyone's going to have a very very long life. But at each stage there are certain key things that are important to talk about and we'll start with the young child. At that point we're making sure that parents understand what benefits might be available through the developmental disability system, through public school benefits, and making sure that the child and the parents have access to every type of resource for appropriate therapy, developmental and behavioral therapy, as well as public school benefits that can be extremely valuable in young childhood.

We also will start to talk about that vision for future care and quality of life and what the costs might be, although it's a little hard. Our crystal ball is a little cloudy in the very young ages of a child with special needs. As that individual ages though between age 15 and 16 there's some big transitions that can occur. One of those is that public school services are now by federal mandate to focus on transition to adulthood. So we want to make sure that that individualized education plan is very focused on making sure that the individual with the special needs has access to learning skills that will be needed as they become adults and transition in their early twenties. We're also going to take a look at again what are the future benefits that might be available, especially after age 18, because after age 18 mom and dad's income and assets are no longer a factor in eligibility for things like Supplemental Security Income, Medicaid, and certain other types of developmental disability programs, including vocational programs. And then the last thing that we talk about in that age 15 to 16 is to begin to talk about are we going to need a guardianship or whether there's power of attorney designations that are needed, and what does again that vision look like as that individual transitions to adulthood. It's not too soon to start talking about it between age 15 to 16 because we're going to need to implement all of that at age 18. So we begin that conversation during that time period.

At age 18 everything changes. At that point legally the individual with the special need whether it's a physical, emotional, developmental disability, regardless of the special need is now considered an adult and independent. And so it's important at that point for parents to be ready to either implement power of attorney documentation for financial and health care decisions or perhaps proceed with guardianship. We're also going to want to actually apply now for Social Security benefits like Supplemental Security Income, Medicaid. We're going to explore vocational support services and adult developmental disability services, which may give different programs than for individuals that are minor children. So we want to look at the adult programs at that point. We're also going to seriously begin talking about the transition to adulthood. There's no right or wrong answer to that but as you can imagine the financial implication of transitioning someone you love to a more independent living setting is different if they transition perhaps in early adulthood so before age 30 versus if they transition at age 50 when mom and dad are 80. So we want to make sure that we have the vision for that family, what that transition is going to look like. That conversation has started, and we begin to quantify the costs that are associated with that type of transition.

And then the last stage is essentially the age when the parent retires. And the reason that's important is because at that point assuming that the child was declared to be disabled prior to age 22, there are additional benefits that are available to that individual. Dependent benefits, Medicare may be available. And at that point also we're having serious discussions about successor transition. So the next generation that's going to provide the care and the love and the support and the time for that child when mom and dad are no longer able to do that same type of support that they're doing today. Obviously all during these stages you'll see the same themes of discussion. But there are very clear times that things need to occur in order to have the best possible outcome for your individual that you love and to make sure that their care and quality of life is preserved.

So as we go through the planning process the next step is really understanding the needs and the vision. So if I could have the next slide. So there's some really important components that we recommend here at National Care Advisors that need to be discussed prior to talking to your financial planner and your attorney. Obviously the medical care and access to health insurance, that's very important whether you're going with private health insurance or Affordable Care Act or you're going to rely on Medicaid or Medicare. The big-ticket item is always that custodial care, personal care, and supervision that's required if an individual cannot live independently. Supplies and equipment. Those that are going to be covered by health insurance and then of course we know that there's always something that has to be out of pocket. We want to quantify that for you. Housing. Of course, where is this individual going to live in the short term? What is the long-term vision? Are they going to have a home that's provided by family funds? Or are they going to go to a high quality group home or perhaps a supported community setting? There are lots of wonderful options. And that's a changing landscape all of the time depending on where you live and where retirement occurs and all those kinds of things. And certainly that's important to understand that vision and the associated costs. Transportation, it's important not to have someone in the family have to interrupt their day 9:00 a.m. and 3:00 p.m. to get the individual with special needs where they need to go. So we want to make sure that we've considered the costs of transportation in the current and future. Vocational support. Of course we all get immense socialization, emotional, and obviously financial benefits from being employed. We want to make sure that everyone with special needs has meaningful activity during their day as adults. And so we want to look at those vocational supports. Both those provided through government resources and also sometimes private pay. Socialization support for, oh my gosh, having fun, getting out to the movies and the mall and going out for dinner and enjoying time with family and friends. We want to make sure there are costs associated with that if they need a companion to go with them, that we've considered that. And then finally specific quality of life factors. This might include the fact for your family that it's important to have a companion to be available to go to church services or religious services of some kind. It might be something as simple as you want to make sure that—we had one family it was very important that their loved one always had their own television and their own TV changer, because that brought them immense quality of life and pleasure to be able to control that in a world where they could not control a lot of other factors in their lives. So that conversation of understanding the needs and then projecting the costs is very important. We want to make sure that the right amount of funding is placed in that special needs trust. Sometimes we see that those special needs trusts are overfunded or underfunded. So as we're projecting the costs we want to simplify that a little bit because there's really only three ways that things get done. It's either going to be through unpaid family time, love, devotion. Third party benefits through the government, Social Security, developmental disability, Medicaid, those types of services. And then the last one of course is family funding. So to understand current and future value of benefits we certainly could do a whole nother webinar on this. But Supplemental Security Income and Social Security Disability Income do provide monthly income, certainly replacement for individuals that cannot work in an independent setting. To give you an idea, Supplemental Security Income in 2022 is going to be $841 per month in most states. There may be some state supplements as well but that's the baseline, is $841. It's a supplemental plan, not going to cover everything. We also want to make sure that you're fully aware of the dependent benefits and survivor benefits that could be in play for a loved one, a child certainly, of adult parents. There are Medicaid and Medicaid waiver services. Those are so important, because as I mentioned earlier the largest line item is going to be the long-term home care and aide services. And so the only really excellent payer source to help with the cost of that care is going to be through Medicaid and Medicaid waiver programs. As well as developmental disability services. So we want to make sure that we've explored those. Those programs that make sense and are huge value, that we've maximized those for your loved one. And then Medicare can also come into play as another source of health insurance in addition to Medicaid, certainly after mom and dad have retired.

It's important also for us to value the family time and services. I would say that our experience here at National Care Advisors is that parents traditionally undervalue what it would take to replace that parent for the additional time and services that are provided to their loved one. And so we want to have a very objective analysis of that so that we make sure that we have our special needs trust funded appropriately. And then the final step is to develop an expenditure plan in today's dollars for all the other costs that aren't going to be reasonably covered based on what we know for today by third party benefits and by other successor family members that may be willing to provide some support and supervision. I hope this has been helpful, and I'm going to now move on to make sure that Meredith can jump in here, talk a little bit about as well.

GREENE: Thank you, Ann. Yeah, I just wanted to share a little bit of my personal perspective as a special needs planning attorney but also as a parent so much of what you said, Ann, resonates with me, and that there are times where I am woken up at night with fears of how am I going to provide for my family, not just Connor, but my other children. I need to make sure that I have a plan in place, because as you said the role that I play, the advocacy that I do, it needs to be filled in, backfilled as you say. And I don't necessarily want my other children to be burdened by that responsibility. So I need to have a plan in place that has enough resources and enough other tenets to it so that my other three children can choose the role that they want to play with Connor, so that they can be his sibling, but if they want to take a more active role, if they want to take on caregiving, if they want to be involved with advocacy that they can choose to, but not to the detriment of their own life, their own goals, and their own family. So it's very important that you have this plan in place and that you talk to your other family members who are going to play these roles so that everybody feels comfortable with the plan so that when something does happen to Tom and I Connor is taken care of and my other children feel comfortable with the role that they want to play.

KOERNER: We often say that that's the best gift that you can give to your children, all children in the family, is to make sure that you've got a plan in place with the vision and with the funding so that in the future everything goes smoothly.

DESAUTELS: Great transition, thank you, Ann. Meredith and Ann, thank you so much for talking to us about the quality of life, sharing your experiences and your story. It's a lot of information in there, Ann, birth to death and a lot of things to consider. Meredith, I really appreciate you being vulnerable with all of us and sharing Connor and your family's story. I think it really helped bring it to life. But as Ann said, now I want to transition into the next part of that discussion to talk specifically more about the planning aspect. So after you've created that vision that we just talked about, Kelly, could you tell us a little bit more about the planning aspect and things that our viewers should consider or think about?

QUINLAN: Absolutely. So you'll see this slide and this slide provides an overview of what we would refer to as your special needs planning toolbox. It is not exhaustive by any means but it can serve as a high level summary of some of the legal and financial documents to consider putting into place when planning for yourself and for a family member with special needs. So for today's discussion we're going to focus on the left-hand side of the screen and do a deeper dive into special needs trusts as well as ABLE accounts. But if you look at the right-hand side of the screen it's important to note that in addition to our team providing education and guidance on special needs trusts and ABLE accounts, our team also spends a significant amount of time talking with our clients about other important topics such as health care powers, durable powers of attorney, as we said different types of trusts, the importance of beneficiary designations, trust funding considerations, and types of trusts that may be better suited to fund a special needs trust. As I said but for today's discussion we're going to be focusing on the left-hand side of the screen. And we'll now talk you through different types of special needs trusts as well as ABLE accounts. So I'll turn it over to you, Jonathan.

DESAUTELS: Okay, thank you. Kelly, maybe this is a good opportunity for me just to pause and ask maybe one of the viewer questions that came in. So we got a lot of questions regarding special needs trusts. So Ken and Meredith, maybe one of you could share. Is that something Day Pitney focuses on and helps customers with?

SHULMAN: Yes. We consider them clients rather than customers but let me try to address that. But let me take a step back first because we only have about five or eight minutes to talk about a very complicated subject and I think we need to put this in context initially. What are special needs trusts and why do we have them? As Ann suggested, a number of the programs for people with disabilities were grafted onto poverty level programs. For some but not all of those programs a person needs to be impoverished to be eligible for them. And in determining impoverishment the government programs divide things into what they call countable resources and noncountable resources. And a lot of these entry level programs like SSI, Supplemental Security Income, and Medicaid, one can only have $2,000 in countable resources. The funds in a special needs trust if the trust is properly drafted and properly administered are considered to be noncountable resources. That is they don't count against that $2,000 eligibility limitation. And so what is a special needs trust? In its simplest form it's a purely discretionary trust where the trustee is given the power to spend the money in the trust solely in their discretion based on what the trustee's determination is of the beneficiary's best interest. It's unlike a typical kind of trust that we would draft, that Meredith and I would draft, if there were no special needs considerations. A more typical trust says the trustee shall use the funds for the beneficiary's health, education, maintenance, and support. If that standard, what lawyers calls an ascertainable standard, were in the trust document, the public benefits authorities would say, "Mr. Trustee, Ms. Trustee, you have a duty to use those funds according to that standard for the beneficiary's health, education, maintenance, and support. That being the case, the resources in that trust are countable and you need to spend them all in the beneficiary's well-being. Come back to see us when there's only $2,000 left. And we'll consider putting your beneficiary on public benefits." So special needs trusts are purely discretionary trusts and there's going to be a lot of repetition going forward with the rest of this program where Meredith and I are both going to say the selection of the trustee is critically important. And you can see why that is the case, because all distributions from the trust are purely discretionary.

That means the trustee has to be an active trustee. They need to understand what benefits programs the beneficiary is on. Some are not means-tested. And certain kinds of distributions can be made with no impact on the person's eligibility for benefits. For instance DAC benefits, which Ann mentioned, disabled adult child benefits based on a parent's earnings record, are not means-tested. One could have more than $2,000 and still be eligible for those benefits. That does not suggest that a special needs trust may not be appropriate, however, because the special needs beneficiary may not know how to handle finances, may be vulnerable to exploitation, and those kinds of things. Which leads me to remind all of us that special needs trusts are not done in isolation. They should be integrated into your overall estate plan. All of you on this seminar have an interest in special needs and have a loved one, one would suppose, with a special need of some kind or the other. So you have that in common. But some of you are going to have tax issues to consider, estate tax issues or income tax issues to consider. Some of you are going to have charitable inclinations. Some of you are going to have other children and you're going to wonder how to divide your estates between your special needs child and your other children. So again it has to be a holistic approach where you take in to consider all of these things. Meredith and I are often asked to draft a special needs trust in isolation and we have to inform the client it just doesn't work that way. We really have to consider everything. And I would also say that the estate planning process itself answers the three questions, the three topics that Kelly and Jonathan started with. We talk about the future. We talk about funding. We talk about the issues of guardianship and whether one needs to be appointed for your loved one. As Meredith suggested, the guardianship issue I think more than the financial issue often keeps the parent up at night. Who is going to advocate and provide for my child when I'm no longer able to do that?

So the best utilization of the special needs trust is to provide funds that do not interfere with eligibility for public benefits and help enhance the beneficiary's quality of life. These can be anything from additional medical care, residential kinds of situations, tutors, traveling, quality of life kinds of issues. Because as Ann suggested, the SSI maximum payment if the state doesn't supplement it is around $850 a month in 2022. Some states supplement and I don't know any state that it's more than $1,000 a month. So it's not enough to live on obviously. And another source of funding through your financial advisers, through your planning with your lawyer, this is what really can enhance the quality of life.

So there are three kinds of special needs trusts and I'll do this very quickly because I know we're short on time. Most of our clients are going to do what we call third party special needs trusts. Those are trusts created by typically a parent or grandparent or aunt or uncle who provide the supplemental funds in a special needs trust for the benefit of their disabled child, grandchild, nephew, niece, whatever it might be. And that's going to be part of the basic estate plan. That's really the core of what we do. Once in a while, and I don't want to go into too much detail on this because it's really quite technical, a beneficiary who is on a means-tested benefit receives an inheritance or a malpractice settlement or some gift from a well-meaning relative that puts them over the $2,000 asset limit. And in that case in order to stay on the program if one transfers the property they have to transfer it to a first party special needs trust, which requires, has many of the same terms, but requires that at the beneficiary's death any funds remaining in that trust have to be paid back to the government, to the Medicaid provider. So if we do good estate planning we should never be doing a first party special needs trust because we do not want to have a payback requirement.

The other thing I would say about the trust is given the purely discretionary nature of the special needs trust it's really important, and again this is repetitive, to give lots of thought about who the trustee is going to be. It has to be someone who is willing to investigate the sources of funding, other sources of funding, someone who keeps current on the law, someone who either knows the beneficiary very well or has the wherewithal and the understanding to find people like Ann who can provide support and assistance in evaluating what the needs of the individual are. It's also helpful as parents or grandparents who create these trusts to prepare letters of intent to the trustee, which can go from the granular, because again the trustee is not going to know your child the way you know them. It can go from the granular. Name, address, Social Security number, allergies, who his doctor is, who her therapist is, who her friends are, where she lives, all of that sort of granular important stuff that it's very important for a trustee to understand, including what government benefits the person may be on. And then something more not speculative but in a sense of what you would like, how you see your child progressing, how you would like to see the trustee use this money in that discretionary way for your child's benefit.

As a trustee I can tell you that's incredibly important to me to know what the parents' aspirations are for their child, because again full discretion really is a vanilla wide-open standard. It says to the trustee, "Use these funds for the benefit of my child," but it doesn't give really any standard to do that. So I think I will stop there for a moment and see if Meredith wants to supplement what I gave this introductory session on of special needs trusts.

GREENE: Sure. Just quickly again from my own experience. I have a special needs trust for Connor that will receive the inheritance that he gets upon my husband and my death. And the one thing that gives me comfort is knowing that that special needs trust is very very flexible and is designed to grow with Connor. It can provide the base supplemental things he needs like housing, transportation, etc. But it's also supposed to provide for all of the fun things, the things that make his life wonderful and joyful and worthwhile. So it will hopefully pay for a vacation on Cape Cod because that's what's meaningful for us. It can provide for him and a caregiver maybe to go out to Colorado to visit a family member or to go to Europe or to buy that sixth iPad of the year because he keeps breaking it. Whatever it is that is going to make Connor's life meaningful that I'm providing now, that's what the trust is going to provide later on. And as long as I have a trustee who knows how to administer that in the best way possible for Connor, this trust is not restricted at all. The trustee is going to be able to use the funds specifically in a way that is beneficial for Connor, not anybody else, but for Connor. So it's very personalized.

SHULMAN: I'm sorry. Meredith, I wanted to add one thing to that which I forgot to mention, is you and I very often work with clients who say, "We're really not sure. Our son or daughter has some mild developmental disability. We're really not sure if they're going to need public benefits or not. We hope they don't. We hope they launch. We hope they're independent." And I think we could sum up our philosophy is that we hope for the best but we plan for the worst. Because we don't know even with people who are on the margin of being independent or not whether they really will have the wherewithal to manage funds in the future, whether they may have a digression or they may not mature or recover or progress as much as the parents had thought and they may need public benefits. The thing about these special needs trusts is they're not just, and I want to emphasize this, they are not just for people who are on means-tested public benefits. As Meredith said, they can be very flexible. They can grow with the client and his or her needs. And they are not just restricted to keeping the person eligible for public benefits. Many of you in this audience may have sufficient needs and your trust will be large enough that special needs trusts and public benefits are not really an issue. But others want to preserve that eligibility. So I wanted to make that point.

GREENE: Yeah, thank you, Ken. Ann, did you want to?

KOERNER: Yeah, I think one of the things about preserving Medicaid eligibility is that as we look at the vision sometimes in end of life care again when that individual with the special need is very elderly Medicaid can have some pretty huge value at that particular point. We may go on and off public benefits throughout the lifetime. In addition it's super important to understand that the Medicaid system will never force you to use Medicaid. You can always private pay. And I think that point is sometimes lost, that if there's a special need and you need to take your child to the Mayo Clinic or you need to go to some really specialist that doesn't accept Medicaid no one's going to say, "No, you can't use private funding for that point." But on the other hand there is huge value and as part of the planning process we can quantify what that potential value might be and why it makes sense to at least preserve eligibility throughout the lifetime of the individual.

GREENE: Right, and that plays right into the next slide where we talk about the dos and don'ts of trustees because as Ann said the trustee may decide that Medicaid isn't the proper funding right now and maybe private insurance is worthwhile. So your trustee needs to understand what they can and cannot do. So there are all of the rules and regulations that a typical trustee of any trust has to follow. Ken already went through that. The trustee has to invest, they have to follow the prudent investor rule, they have to file taxes, they have to file accountings. A trustee of a special needs trust also needs to report to government benefits based again on what government program that person is on. So if you take my child, Connor might be on a completely different set of programs than any of your loved ones are on. And the rules for every single government benefit are completely different. So the trustee needs to understand those rules and know how to administer that trust. So again similar to using private insurance instead of Medicaid, if your child is on SSI and the trust or someone else is providing for food and shelter, well, SSI is going to be diminished. But it may be that that's worthwhile. Maybe taking $250 less in SSI but having a better and more safe housing experience is worthwhile. And the trustee needs to understand what those ramifications are because they don't want to follow a strict line rule of we can't impact government benefits, because that's just clearly not the case. It needs to be a very personal decision as to what is best for your child.

One of the general rules is typically not to distribute cash directly to that beneficiary but to pay the bills directly. So for instance if Connor is living in a condo somewhere I expect the trustee to pay the condo fees, pay the mortgage if there's a mortgage, pay the utilities directly. Connor is not going to pay them. The trustee is not going to put money into an account where Connor then pays those bills. So you need to be aware of all of the different aspects of the government benefit and have a trustee that is on the ball, who knows the rules and is capable of doing this on a daily, monthly, quarterly basis depending on how much need your child has and again that's going to vary from person to person.

Another thing that the trustee is going to decide is do we take out a life insurance policy for that caregiver so that when the caregiver dies there's a life insurance policy owned by the trust so that there is an influx of cash to pay for a professional caregiver if that's needed at that time. So again I'm not going to harp on this too much, I know Ken did a great job on trustees already. But just know that the trust is very flexible. It's supposed to clearly benefit your child and you need a trustee who's going to appreciate all of the ins and outs, the dos and don'ts.

DESAUTELS: Thank you, Meredith, Ken, Ann. That was fantastic. I know we got a lot of questions on ABLE accounts. So Kelly, do you feel comfortable spending a couple of minutes just talking to the audience about ABLE accounts in general?

QUINLAN: Sure. Absolutely. Yeah. So in addition to special needs trusts we also get a lot of questions about ABLE accounts. So let's start with some basics. So what is an ABLE account? So ABLE accounts were created by legislation that actually passed in 2014 and it's called Achieving a Better Life Experience Act. And they're modeled after the 529 college accounts. And they were created primarily because parents and guardians raising a child with a disability or a working age adult with a disability often found that there were extra costs associated with that disability that exceeded the amount that they were receiving from public benefits and they just didn't have enough funding available to pay for these types of costs. So for example Meredith mentioned an iPad. So these types of accounts are designed to supplement those types of costs. Assistive technology, computers, hearing aids, communication devices, wheelchairs, and vehicle modifications are just a few types of expenses that typically exceed the value of a benefit that an individual is eligible to receive from the government.

So an ABLE account, what is it? It's really a way for individuals with disabilities and their families to save money, invest money, pay for certain qualified expenses, and remain eligible for public benefits such as Ann mentioned, SSI or SSDI. And like Ken mentioned a special needs trust—I mean an ABLE account, it has the same idea of a special needs trust. It's really—and you'll hear these words quite frequently—it's to really supplement but not to supplant the benefits that a disabled beneficiary is entitled to receive. Now most states have their own ABLE account options. And all ABLE accounts are generally created online. So a question that we typically receive on ABLE accounts is is there an age requirement. And the answer is yes. So an ABLE account can only be created for an individual who has a documented disability that developed before the age of 26. So that's very different from special needs trusts where the special needs trust can be created for anyone of any age.

Who can create an ABLE account? So an ABLE account can be created by the disabled beneficiary themselves assuming that they have capacity and are over the age of 18. Or it can be created by a guardian or the parent of a disabled beneficiary. The catch is that a disabled beneficiary can only have one ABLE account. So if you have family members across the country that would like to contribute to an ABLE account the disabled beneficiary can only have one account.

Another question we receive typically is are there minimum or maximum amounts that can be added to an ABLE account. And again the answer is yes. So for 2021 $15,000 is the maximum amount that can be deposited or gifted into an ABLE account. And the other thing to keep in mind is that as these moneys in the ABLE account get invested and they grow, if the account exceeds $100,000, it will impact the beneficiary's eligibility for benefits. So let's say if it's $102,000, the benefits that the disabled beneficiary can receive will actually be reduced until that excess is spent down to $100,000. So that's another number that's important to keep in mind.

Another question we receive is what happens on the passing of the disabled beneficiary. What if there's a balance left? How does that work? And on the passing of the disabled beneficiary if there is a balance left in an ABLE account, the balance must first be used to reimburse the state for any Medicaid benefits that it paid out on behalf of the disabled beneficiary. And then if there's a balance remaining after that it can be distributed to others, family members or whatnot.

And then lastly, can you have both an ABLE account and a special needs trust? And the answer is yes. So they're not mutually exclusive and sometimes a combination of a special needs trust and an ABLE account is really the perfect combination for individuals. So hopefully you found that helpful and I'll turn this over to Jonathan.

SHULMAN: Jonathan, it's Ken, before you start could I just interject one thing if that's okay? The distinguishing features between the special needs trust and the ABLE account. Medicaid really pays for a lot of services for people with disabilities. One doesn't really know that because they typically don't send out any kind of annual accounting of what they paid for. But Medicaid pays for group homes, it pays for transportation, it pays for vocational rehabilitation services, for physical therapy, that sort of thing. So people are surprised when the person dies to see how large the payback is to Medicaid very often. Usually it's enormous. And people don't realize that because they think of Medicaid as just a medical insurance program, and my child was really healthy, didn't use much medical care. So as a practitioner, the ABLE accounts we think are really useful and they are useful for more of the short-term kind of thing. But they do have the disadvantage of having the payback requirement. And so if people in the audience are thinking then why do I need a special needs trust if it's simpler to do an ABLE account, that is the downside to keep in mind. We find it more useful for smaller amounts. Use it, refund it, use it, refund it, that kind of thing. So I hope I didn't overstep any bounds.

DESAUTELS: No, not at all, thanks, Ken. A lot of great information shared by each panelist. And if you're like me your head is probably spinning a little bit because we covered a lot of information at a really high level. I've spent a lot of time with the panelists. We could spend hours in each of the individual areas because this is really complex. But what I'm hearing is that importance of the peace of mind and comfort for both parties, for you as the planner but also the person that we're planning for, is truly important. I also hear a level of passion and expertise from each of our panelists which is just fantastic. At the end when we close this down I will spend some time talking about next steps if you have additional questions or you want more information on any of the areas that we talked about today. But I did want to spend at least a couple of minutes just on some of the questions that came in. I know I highlighted it at the beginning. But we received a number of questions from the audience in advance. So we'll get to as many as we can before I close this down. But Meredith, I'm going to come to you first if that's okay. One of the questions that came in was around beneficiary designations. And is that something that our viewers need to think about if they already have a trust set up? And can you have a designated beneficiary assigned to a special needs trust?

GREENE: Yeah, great questions, Jonathan. And this hearkens back to what Ken was saying about taking a holistic approach. You can't just have a special needs trust and think you're done. I know for me I have 401(k)s from a couple of different prior employers. I need to A, roll those over so they're more consolidated. But I need to make sure that my 401(k), my retirement accounts, have a beneficiary designation such that Connor's special needs trust is designated. I can't have Connor receive my retirement plan outright. I need his trust to be designated so that any of that share of retirement accounts that is going to go to Connor's trust goes directly to Connor's trust and not to Connor outright. Similarly with life insurance policies, I can't have Connor be an outright beneficiary of my life insurance policies. Those policies need to be changed, the beneficiary designations, so that any share that I want Connor to receive goes to the Connor Greene special needs trust and not to Connor outright. So you really want to make sure that you have a clean estate plan and that you get all of those beneficiary designations updated and you make sure that your child is still going to be eligible for those government benefits. And so that he doesn't have more than $2,000 of assets in his name, his trust can be flush with all of that inheritance.

DESAUTELS: Thank you, Meredith. So maybe we got time for one more, and Ann, I'm going to come to you. And in advance I'm going to stack two questions into one here. We got at lot of questions, and I know Ken spoke a little bit about the primary caregiver. But we received a lot of questions from the audience about how they support a loved one when they're not the primary caregiver, so maybe a grandparent, another relative, even a friend. How can they help somebody with special needs either financially or in terms of longer-term quality of life, question one? Question two, anything that they should consider if they are living in a different state?

KOERNER: Okay. Well, that's a complex question.

DESAUTELS: And Ann, you've got three minutes.

KOERNER: All righty. So I think I'll start with the first one, and that is talking about how can you help support. And I am a firm believer and our most effective work with our clients is when we actually involve multiple family members in the discussion. And we often say that when we're creating the vision, when we're talking about the future and successors, we want to encourage family members to involve aunts, uncles, siblings, anyone that they feel appropriate. We call them dining room table discussions. But that's super helpful so that we have everybody on the same page about not only what the vision is but what role they might like to play in the future. Obviously for financial support given that we can't all provide a lot of time and energy, we certainly can provide our love, but for the financial support obviously it's very important that aunts, uncles, grandparents, even adult siblings if they want to help that they also have beneficiary designations, or that they understand that a special needs trust exists. And so this is a multigenerational estate planning process, it's not just, as Meredith and both Ken have said, it's not just about the immediate parents.

I think for caregiver support one of the things that we like to see is that we are introducing paid caregivers and that the individual with the special needs gets used to having folks other than mom, dad, aunt, uncle, cousin as a caregiver prior to the need for that actual transition. Some of the toughest cases that we work with is when there has been no planning, no explanation of the vision, and then we have a key parent caregiver pass away or become ill, and they can no longer provide care. So now we've got the crisis of an individual with special needs who doesn't really understand everything and can't process it all. Not only have they lost the services of that parent, but we've got to now introduce them to paid caregivers. So we want to talk about what that plan or what that transition looks like. Whatever is the right time for that particular family based on what their vision is for care and quality of life.

The last piece you mentioned is the out of state piece. And certainly the wonderful thing about a special needs trust is it's federal law. And so while there are nuances in each state, and certainly Ken and Meredith can help with that, and we do want to make sure that we have appropriate legal counsel if we've got a multistate situation, generally speaking the rules that govern special needs trusts and special needs administration are fairly similar from state to state at a 10,000-foot level I guess I should say. The basic concept of being able to shelter funds to preserve access to means-tested benefits. But again it's important that if you have an out of state family member that wants to contribute to a special needs trust they know how to do that. And so that's important to understand from the attorney and from the financial planner that you're working with also can also guide through that process.

There's really no restriction on out of state money. That is not a problem in my experience and I'm sure that Meredith and Ken can say the same thing. As long as it's directly to the trust and not to the individual. That's where we get into trouble. I would also say that we're all mobile. And I don't have a crystal ball either. And part of this planning process is not only to create the vision but to have a formal way of looking at that plan so that you can reevaluate it at least once a year. A lot of folks do it around New Year's. And you can see okay, am I planning on retiring, I didn't think I was going to retire in Florida but now I am. Or I didn't think that all the siblings were going to move across the country because they got great job opportunities but now that's a new factor. So again when you're looking at out of state I think we almost have to make sure that we've planned for that flexibility. And so that we can then make adjustments on an annual basis. And again after doing this for maybe 20, 25 years, I have to say that the families that have those types of plans in place are in a really good position when they do have to be flexible because life happens. So thank you so much for those questions.

DESAUTELS: Thank you, Ann. I guess we know what you're doing on New Year's. So with that and keeping an eye on time, I think we're going to wrap up today. What I heard was that one size doesn't fit all. There are a lot of unique situations that are out there. For me the three key takeaways are one, creating the vision. Ann and others talked a lot about the importance of that for the family. Number two, understand what role your family members want to play in that vision. And number three, if you think about the financial strategy aspect of it, how are you shaping your family's planning toolbox as Kelly mentioned? So first and foremost, thank you to our esteemed panelists. Ken and Meredith from Day Pitney. Ann from National Cares. And Kelly from Fidelity Investments. Special thanks to all of you viewers. We hope you found this session information and allowed you to think about your specific plan and conversations you might want to have with your

Fidelity representative, your attorney, and perhaps maybe a tax adviser in the coming months. We want you to know that planning for a loved one with special needs is complicated. We spent a lot of time on that today. But you're not alone. On your screen you will see the ways that we can collectively help. I encourage you to set up an appointment with us. Get ahead of the changes that might need to be made to your plan. We can help you consider options in light of your individual specific situation. Also please look out for additional educational materials that'll be available in our life events hub on Fidelity.com coming soon specific to special needs planning. And please subscribe to our webinar list. If you want to hear more about these topics and others it's a great way to stay informed. Finally, you should be receiving an e-mail survey based on today's webinar. We'd really appreciate you to take a moment to provide us some feedback. This helps us shape future webinar events. Thank you, everyone. We wish you and your families a wonderful day.

Disclosures

Investing involves risk, including risk of loss.

This presentation is provided for informational use only and should not be considered investment advice or an offer for a particular security. Views and opinions expressed are as of 11/3/2021 and may change based on market or other conditions.

Information provided herein is for educational purposes only and should not be construed or relied upon by you as advice or guidance as to the appropriateness of any investment decision.

Fidelity does not provide legal or tax advice. The information herein is general in nature and should not be considered legal or tax advice. Consult an attorney or tax professional regarding your specific situation.

Wealth Management Advisors are registered with Fidelity Brokerage Services LLC (FBS) and licensed with Fidelity Personal and Workplace Advisors LLC (FPWA), a registered investment adviser. Whether a Wealth Management Advisor provides advisory services through FPWA or brokerage services through FBS will depend on the products and services you choose.

The CERTIFIED FINANCIAL PLANNER™ certification, which is also referred to as a CFP® certification, is offered by the Certified Financial Planner Board of Standards Inc. ("CFP Board"). To obtain the CFP® certification, candidates must pass the comprehensive CFP® Certification examination, pass the CFP® Board's fitness standards for candidates and registrants, agree to abide by the CFP Board's Code of Ethics and Professional Responsibility, and have at least three years of qualifying work experience, among other requirements. The CFP Board owns the certification marks CFP® and CERTIFIED FINANCIAL PLANNER™.

The Certified Wealth Strategist® (CWS) utilizes a blended learning approach that includes instructor-led training, 13 Wealth Management Issues study guides, online mastery exams, conversation skill builders, and eLessons. The learning experience culminates with a Capstone Project: a written document demonstrating a sustainable framework that applies the new knowledge and skills to the practitioner's business. To be eligible, a candidate must have received a degree from a four-year accredited school and have three years of client-centered experience in the financial services industry.

Services from the Fidelity Center for Family Engagement are currently available on a limited basis.

The Fidelity Center for Family Engagement is an affiliated business unit of FMR LLC and operates externally from Fidelity Brokerage Services LLC.

Fidelity Charitable® is the brand name for Fidelity Investments® Charitable Gift Fund, an independent public charity with a donor-advised fund program. Various Fidelity companies provide services to Fidelity Charitable. The Fidelity Charitable name and logo and Fidelity are registered service marks of FMR LLC, used by Fidelity Charitable under license.

Fidelity Brokerage Services LLC, Member NYSE, SIPC, 900 Salem Street, Smithfield, RI 02917

1004289.1.1