This talk will cover both Federal and State law. No attorney-client relationship is established by the provision of any information in this podcast.

**Estate Planning**

What is estate planning?

Estate planning is a process of putting a plan into place and goes far beyond the creation of a will and trust documents. It includes assets, contingency plans, roles for various people -- the same kind of planning that would occur if you were running a small business. It is about documenting how your personal affairs would run if you were incapacitated or deceased.

Planning can be overwhelming, and special needs families are already exhausted, but it does give you a big say in what happens to you, your loved one, and your assets when you cannot actually say what should happen next. If you do not make a plan, your local courts will make a plan for you. State legislatures create and enforce plans for people who don’t have a written plan.

Assets can end up with people you do not expect/don’t want, and you can lose out on opportunities to protect assets for your loved ones in addition to saving taxes and other good benefits.

Most common documents for estate planning:

- Will (least important document, actually)
- Trusts
- Durable Power of Attorney (for financial decisions)
- Health Care Proxy (for health care decisions)
- HIPAA authorization (medical records release – allows communication between third parties and medical providers)
- Guardianship and conservatorship appointments and nominations – may be able to name your successor if you currently are a guardian or conservator to someone in your family.

Will: Specifies distributions of assets and nominates a personal representative/executor who makes sure that the terms of the will are followed. Responsibilities last for a year or less. A will in many states can nominate a guardian or conservator of minor or incapacitated child.

Wills only take effect once you die.

(Slide 7)

A will only covers assets that will go through Probate.

Many people think avoiding probate is the most important estate planning objective when, in fact, it is probably the least important. Sometimes we want to use probate to make sure assets get left in a certain way. What matters when planning is to hyper
focus on what your goals are and concentrate on getting there. There are many paths to get to that goal.

The probate process often makes people nervous because it has to do with going to court. If you can avoid court, that is a great goal as it keeps your private information private.

In Massachusetts, a will must be probated even if it does not govern any assets. All states have different rules about this that should be somewhat similar. The will must be allowed by petitioning to the court, and then the personal representative/executor will be appointed. The personal representative/executor must do the following things (Slide 8):

(1) Gather assets and figure out what was owned at death
(2) Give notice to creditors, heirs at law and beneficiaries of any trusts
(3) Need to pay any income and estate taxes
(4) Pay debts of decedent
(5) Make distributions to beneficiaries
(6) File account and close probate.

What is your will going to control? (Slide 9)

A will may govern all, some or none of your assets. You have virtually complete control over how that happens. A good estate plan can actually take a look at all of your assets and figure out which should go through probate and which should go in a different direction. Probate will address anything that you hold individually at your death. It is easier to talk about what assets do not go through probate.

(Slide 10)

Non-probate assets are most of what most people own

(1) Any jointly-owned assets (ex.: bank account)

(2) Assets with death beneficiary designations with people still alive to inherit them (ex: bank & investment accounts, qualified retirement plans, life insurance, annuities, some savings bonds)

(3) Real estate where ownership interest is for life and a living person has a remainder interest

(4) Any assets owned by a Trust – if you have funded trusts during lifetime, those assets will not go through probate.

(Slide 11)

Many people think trusts are complicated, but they are not for just the Rockefellers anymore. Do not need to have a ton of assets to take advantage of trusts. It results in
a private process instead of a public one. Only the people involved in the trust get to know what is in them; if they go through the will, then they become part of the public record and can be searchable by creditors and other interested parties.

Trusts can manage assets during your lifetime and even after you die. It’s a good way to manage assets for people that you love – “reaching through the grave.” They also can provide asset protection for irresponsible or vulnerable beneficiaries from themselves. They can do some estate tax planning and reduce or eliminate any estate taxes that may need to be paid. They also can plan for long-term care needs while considering a disabled person’s public benefits. Can also provide for any charitable intentions – if you can dream it, we can write it in a trust. It can be very creative.

(Slide 12)

Who acts as a trustee? Anyone can be your trustee, and you get to say via planning who can manage things during your lifetime as well as once you are gone. You can be your own trustee; can also be friends, family members, institutions (banks and trust companies), sometimes beneficiaries or guardians. There are pros and cons to this decision. It’s a very individual decision.

(Slide 13)

**Revocable living trust (“RLT”):** This is where your will pours over into a trust. Anything put into the trust during your lifetime is not governed by will, but some people decide not to fund the trust until the time of death. If the latter, your estate goes through probate and the trust will be funded at that time (after death). It can provide for centralized asset management during your lifetime; if you are not able to manage your assets, this is a good way to have someone help you with that. It works much better than powers of attorney, which are financial contracts with an agent who can do financial transactions for you, because powers of attorney do not work well at the bank, especially as you get older. Banks are afraid to take the power of attorney and allow you to use it because they are concerned it is not still valid. They are much less skittish when it comes to trusts.

RLT cannot manage IRAs and qualified retirement plans. They can also avoid probate if funded during your lifetime. They also can be estate tax planning vehicles – can reduce or eliminate estate taxes for married couples.

Estate tax can be state (not every state has this) or federal; each person can have an estate up to $5.34 million and not have a federal estate tax levied on their state. For a couple, estate can be $10 million and no estate tax required to be paid.

Estate tax is a death tax levied on your estate before you can pass it along to your beneficiaries. Most people find it pretty appalling, especially because you have already paid income tax, sales tax and capital gains tax throughout your life. The federal estate tax rate is 40%.

Federal law favors married couples; can only do this kind of estate tax planning in a RLT unless you are married.
RLT Provides for succession of management (trustees)
Can be extremely flexible – if you can dream it, we can write it
Can provide for lifetime asset protection, divorce protection, and public benefits protection. Cannot provide asset protection for you, but if you leave assets in trust for your children and they keep it in trust, then that money can be protected from creditors and from divorce, depending on state law. Next generation also does not have to pay estate tax on the money left in trust to them.

What a RLT cannot do – cannot provide asset protection for creator of the trust
Cannot provide long-term care for you, only your children and beneficiaries.
All assets put in are still your assets until you die.
When creating an estate plan, are incapacity documents appropriate?
- Power of Attorney is still important for retirement assets; if you were disabled, there should be someone named as an agent who could figure that out.

Some states have HIPAA language within health care proxy, but often better to have a separate HIPAA authorization. Health care proxy is a springing power. Only goes into effect when doctor says it should. HIPAA authorization allows people to get medical information and discuss that information without anyone needing to be incapacitated. This is very important when children are in college; otherwise, would need a release for their personal health information (PHI). Having a HIPAA authorization that does not require incapacity is a very good thing once they are over 18.

Powers of Attorney generally are present powers concurrent with the principal. Power of Attorney documents are governed by state law. Every state has their own law, but most have let go of the idea that Powers of Attorney are springing. As soon as a Powers of Attorney document is signed, the person named will have the same set of powers as you do. This person could walk into a bank and empty out your bank account, and this is what makes banks very nervous. Banks therefore like to have powers of attorney coupled with a trust.

Powers of attorney may be revoked or overruled by you at any time, either verbally or in writing. Powers of attorney document is only good during someone's lifetime. Have a list of people named as potential agents; if person you named cannot act on your behalf, then you need to have a backup.

Powers of attorney are cookie cutter and widely available on LegalZoom and other online sites (be sure to find one specific to your state); however, if you do that, there are often several powers that are missing or not drafted well for your situation.
Slide 18 – Health Care Proxies

This is a springing power which goes into effect when the physician says that the patient cannot make or communicate informed medical decisions. Because of that, it is not effective for day-to-day decision making. Generally, not helpful for situation where health care decision making is urgently needed. Best used in situation where someone can make their own health care decisions, generally speaking, except in emergencies.

Most hospital forms are effective about 95% of the time. They are better than not having anything. If you don’t have a designated health care agent or power of attorney agent, someone has to go to court to obtain guardianship and/or conservatorship to have the authority to make legal, medical and personal decisions for you. Proper planning helps avoid that unseen possibility.

Slide 19 - HIPAA authorizations – discussed above

Authorizes information to be shared with any people that you want it to be shared with. Good document to have for just about anyone – allows you to be able to share information.

Slide 20 – Other health-care related documents (state-specific)

- Advanced Directives
- Living Wills
- Do Not Resuscitate/Intubate orders

In Massachusetts, there are no living wills or advanced directives regarding end-of-life decisions; they are not enforceable. Massachusetts requires that people choose a good health care agent to be sure that their wishes are known to the health care agent. DNRs must be documented in the health department and must be on record in order to be valid.

Slide 21 – Massachusetts law re: guardianship. This is very state-specific.

In Massachusetts, parents may appoint (instead of merely nominating) a guardian for their minor children as well as their incapacitated adult children. Whether the parent is alive or dead, this document will be given effect by the court. This is new as of 2009 and is a big improvement in the law.

Most states have adopted some form of the Uniform Probate Code, which has these appointment provisions in it. Allows parents to choose the person who will step in for you. This form goes a lot further than your will. A will does allow appointment of a guardian for minor children and incapacitated adult children, but it only takes effect when you are deceased. If the parent is not able to care for child while they are still alive, this document takes care of that situation.

Slide 22 – Special Needs Trusts

There are two kinds of Special Needs Trusts. How to distinguish which trust to use really depends on where the money is coming from that is being used to fund the trust.
Third-Party Trusts – funded with other people’s money

First- Party Trusts – for disabled people who have their own money or come into money at some point and need to still qualify for public benefits.

Why are special needs trusts important for estate planning? There are many public benefits that have an asset test. Social security and many Medicaid benefits have a $2000 assets limit. Any assets that you own over $2000 is going to disqualify you from many federal public benefits that are very sorely needed for people with special health care needs and people with disabilities.

Special needs trusts are also important for managing assets of vulnerable beneficiaries and offer creditor protections, divorce protections and protection from other outside threats as well.

Slide 23 – What makes a Special Needs Trust into a Special Needs Trust?

(1) Person must have a disability

(2) Look for language that talks about “supplementing but not supplanting”; that means these trusts are meant to supplement public benefits but not replace them. The main idea of social security is to provide benefits for disabled adults who are impoverished and are only providing basic necessities. Trust is meant to augment basic necessities of life; if it replaces basic necessities, then Social Security would not have to provide the benefit.

Trust should be flexible – sometimes it is ok to affect public benefits or to use trust money instead of public benefits. A well-drafted trust is going to manage that balance just fine. You don’t want to tie your trustee’s hands.

Common mistake: standard for the trustee to make distributions. Must be a wholly discretionary standard for the trustee. That means the trustee could refuse to distribute for anything, even if the beneficiary is homeless and starving. Trustee needs to not have a demand legally be placed upon them.

In many trusts, there is a standard called HEMS: Health, Education, Maintenance and Support. That provides the beneficiary with an opportunity to demand a distribution from the trustee. You cannot have that in a Special Needs Trust; must have a wholly discretionary standard instead. If you already have a Special Needs Trust in your planning, make sure you do not have a HEMS standard in your existing trust. Otherwise, will create problems when you have to turn over the trust document to a public benefits office for review in your area (which is permissible and required for continuation of public benefits).

Spendthrift clause also required – creditors cannot obtain the trust assets, and they cannot be put up as collateral for anything.

Special Needs Trusts – are they right for you?

They have so much more going for them than just being protection for public benefits due to all of the additional protections and management of assets. There really is no reason not to use them. Often, if people are high functioning and do not have
intellectual issues, it is tempting to say they do not need a trust. Best to do planning that can include a trust if you need it and not include SNT if not necessary.

Finally, if the trust is funded and child does not need it, then the money can just be distributed to them; the trustee has the discretion to do that. Generally, there is no stigma attached to the SNT; generally, dependents are already receiving special education services or other services that clearly identify them as a person with special needs.

It is very important to note in slides 27 and 28 the differences between the First-Party Trust with the disabled person’s own money, and the Third-Party Trusts funded by people who love the disabled person.

Third-Party trusts do not have a lot of restrictions on them, but First-Party Trusts (also known as D4A trusts) are governed very tightly by Social Security and Medicaid rules. They have specific rules about who can create them and they can only be created and funded until someone is 65 years of age. It is a great way to fund trust with assets of disabled person and still maintain public benefits, especially when assets are not substantial. Usually see these trusts funded with smaller amounts of money that would wreak havoc with public benefits but wouldn’t be enough to provide for that person during their lifetime.

ABLE Accounts – Massachusetts has not finalized regulations yet. These will be like D4A trusts for smaller amounts of money. This is state-specific, so look in your state to see whether your state has enacted them and what criteria are. In MA, there is a payback provision to the Commonwealth of Massachusetts for Medicaid. Worst part about a D4A trust is that they must have a payback clause to any state that has paid Medicaid benefits for a disabled person during their entire lifetime. The only time they actually get to come in for recovery is when a person has passed away; if there are any assets left in the trust, then they have the right to make a claim and potentially place a lien on the assets they think they need to recoup. This is usually not a very big deal, for if there is a D4A trust funded, recommendation is always to spend that money first. It is really a bonus to use this trust and not lose public benefits, but it is certainly something to be aware of if you are talking about large, substantial sums of money.

ABLE accounts in MA will have the same payback provision, but one of the distinct differences is that SNT D4A (First-Party trusts) have almost no restrictions on what they can pay for, but ABLE accounts have a list of acceptable costs that they can reimburse. It is important to start looking at state law and see what is happening in your state.

Slide 30 – Trustees

It is important to have guidance when selecting trustees. Many people want to run automatically to other children, and it may be a good option, but it is important to think about how typical children are dealing with having a lifetime of responsibility with their disabled sibling. Also, banks and trust companies are not great for acting as trustees for SNTs, for they don’t really understand them, and they get really nervous about not wanting to mess them up. They also have really high minimums. Want to think about
how that will work for you; can have different phases of your life and separate trustees for each one.

You can fund trust with any assets you have, including real estate, cash, retirement funds, life insurance – there is no limit to what you can put in there.

Questions and Answers
Question 1: When is the best time to start the estate planning process? Do you need a certain amount of assets, or is this something everyone should be doing?
There is no right time; being a special needs family is overwhelming and you can only do what you can do. Best to start basic and work your way up from there. If you have someone in your family with special needs that you care about, you should really be thinking about doing your planning now. It is important to address these issues before death or your own disability strike.

Question 2: If you have full guardianship of a disabled child, does that cover durable power of attorney, health care proxy and HIPAA needs, or do you also need those separate documents?
Depends on your state law, but assuming full guardianship means the same thing in your state, then yes, that does cover financial, health care and personal decision making. Some states have split up conservatorship and guardianship (like in Massachusetts), and you must have specific authority over the financial as well as the person under two separate orders from the judge, but in general, you don’t need those other documents if you have guardianship. Guardianship trumps all of that and is a much better way to go because it does not include any shared authority; it is very clear who is in charge of making the decisions.

Question 3: Special Needs Trusts; if parent dies and special needs daughter is in the will, and in the will, parent specifies that the funds will not go to her but will go to SN trust, must that SN trust be set up before parent dies, or is there an abeyance period where the trust can be set up for her after death of the parent so funds can come in as a third-party conveyance as opposed to first-party (due to her inheritance)?
In some cases, you can put language in the will that allows the executor and/or trustee to create the trust for you – this is very state law-dependent. For the most part, though, if you name a trust in your will, it has to exist, so you have to have the trust created in order to name it. By taking care of this in advance, you can use a third-party trust that does not have any payback provisions to the state instead of requiring her to create a first-party trust. Remember also that a trustee or executor might not create a trust exactly as you would have wanted it, so you might want to think about that too.

Question 4: How long does it take from first visit to lawyer until the special needs trust is in place?
Estate planning is a process. Most attorneys work differently, and clients can be very different too. Some people require many meetings to figure out what they want, while others know right at the outset. The average is 6-8 weeks for a case, including process of client understanding what they really want.
Question 5: Adult mito patient who is disabled; past 65; has a trust. At the time trust was set up, did not know that there was such a thing as a special needs trust, and attorney did not advise caller about it. Caller has a regular trust — is it too late to convert to Special Needs Trust? Very concerned about medical expenses associated with mitochondrial disease, specifically the Mito Cocktail. Would something like the Mito Cocktail need to be mentioned specifically into the Health Care Power of Attorney so that Caller would not be denied money for Mito Cocktail?

Trusts created and funded prior to certain laws going into place are grandfathered in and operate under different rules. Caller should sit down with attorney to see whether the situation fits into one of those categories. As for Mito Cocktail, would not need to be in Health Care Proxy or Power of Attorney; those are general powers and do not need to address certain drugs, etc. It can address experimental procedures, but it is more important to let your representative know exactly what you would want. It might not be easy for them to go with the norm. Mito is very individual, and what works for one does not necessarily work for another. Your agent is not going to be able to guess what is important to you, so may want to consider writing things down for them, before you hand off power to them.

Question 6: What are some good resources or networks for finding an attorney who can help with a special needs trust in a particular state?

Answer: There are three attorney organizations:

(1) National Academy of Elder Law Attorneys (also have attorneys who are well-versed in special needs planning)

(2) Academy of Special Needs Planners

(3) Special Needs Alliance

These are member organizations, so people self-select in. May not be the best avenue in your state. If you do use them as a resource, be sure to ask them what percentage of their practice is Special Needs vs. Elder Law. Also ask if they do more than just write trusts. Important to have an attorney who understands social security and Medicaid Rules, guardianship — planning has much more to do with just documents. Need to get an attorney who has a handle on all of the facets of a special needs plan.