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Essential Legal Planning for Special Needs Families

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When families (often the parents) come in to our offices for estate planning their focus is on their special needs family members. Rightly so. The discussion must start with learning about the concerns, desires and goals of the parents as they relate to the special needs family member. We need to learn all about the special family member. Every family is unique, but there are common threads throughout them all and usually their concerns are typical.

At least for a part of the conversation we must change the focus for a moment to the caregivers rather than the most vulnerable family members. Plan for the incapacity of the caregiver as well as the child with special needs. Who will pay the bills if the bill payer is laid up? I'm not just talking about the AFLAC duck, though having disability insurance subsidizing the breadwinner's earnings is a good idea. What about having long term care insurance for the caregivers? Just like the flight attendants advise us: if traveling with small children put your oxygen mask on first before helping others. If we can't take care of ourselves we can't look after others.

Advance Directives and Powers of Attorney

Incorporate powers of attorney, both financial and medical, into the estate plan for the caregivers. A living will directing how they want heroic medical decisions made is important to discuss and have in place. Possibly consider these same legal planning tools for the person with special needs. Don't just presume a guardianship will be necessary for a person with an intellectual or developmental disability. Look for those lesser restrictive alternatives first. A guardianship may be necessary and will be part of the discussion as the child ages into adulthood.

Here is an overview of these documents in the form of a handout I use for my clients:

Advance Directives are legal documents that include a Health Care Surrogate and a Living Will. These documents are generally coupled with a Durable Power of Attorney. These documents provide that your Agent can act on your behalf when making **medical** or **financial decisions**. Your documents should comply with federal HIPAA laws.

HEALTH CARE SURROGATE

The Designation of Health Care Surrogate allows you to name a surrogate and substitute surrogate to make **medical decisions** for you if you become incapacitated or, now since October, 2015 here in Florida, you can allow your surrogate certain authority earlier. Of course while you are able, you will continue to make your own health care decisions. However, there may be times when you are not able to make those decisions. When the surrogate is called upon, he or she is empowered to consult with health care providers on your behalf. The surrogate can give consent for certain treatment, review your medical records, question your doctor or apply for benefits such as Medicare and Medicaid.

The document is important but even more important is the need to discuss your wishes about future medical decisions, life support systems, and artificial nutrition and hydration with your surrogate and alternate surrogate. If they are called upon to make decisions for you, they are obligated to follow *your* wishes and not their independent wishes. It is imperative that they know your values and communication is the best means. You should also speak with your doctor and other health care providers about your wishes. Upon entering the hospital or other health care facility, provide copies of your Health Care Surrogate to the admissions staff and do not sign new documents at the time of admission.

LIVING WILL

The first thought to keep in mind about the living will is that it is effective only if you are in a **terminal, end-stage or persistent** condition. Your physician must verify that you are in a persistent state caused by an injury, disease or illness from which there is no reasonable probability that you will recover.

The Living Will gives your appointed surrogate or alternate the power to specifically limit the scope of treatment, including the withholding of tubes for food and water if your physician states that your recovery is very unlikely, and life would only be artificially prolonged with such tubes. Your surrogate, or alternate, will be able to limit the scope of medical treatment if you become comatose or suffer from a chronic terminal illness, in the same manner that you could refuse such treatment if you were able to speak for yourself. It is very important for you to speak with your surrogate, alternate, and doctor concerning your wishes regarding life prolonging procedures.

If you are living in an assisted living facility or nursing home, you need to ask them their policy regarding Living Wills and Do Not Resuscitate Orders and plan accordingly. A living will is not a Do Not Resuscitate Order (DNR).

These are legal documents and should be kept in a safe place; however, make sure the original document is readily available. We recommend that copies be given to your physicians, family members and friends. In the event you are admitted to a health care facility, a copy should be given to the health care provider to become part of your medical chart.

Once you have completed your Advance Directives, you should not sign another form provided by the hospital or any other medical provider. By doing so you may negate what planning you have done.

DURABLE POWER OF ATTORNEY

A durable power of attorney gives the person you choose (your Agent) the legal authority to handle your **financial matters**. This authority may be limited by you to specific acts. The durable power of attorney must be effective when signed under the current law and remain in effect until you choose to revoke it, you are declared incompetent by a court, you die or another event occurs that suspends or revokes the document. This means that the agent may act for you **at any time**, even if you are competent. The agent is still bound by fiduciary requirements under Florida Law which includes taking only "prudent actions" and exercising caution with a duty of impartiality and good faith.

It will likely be necessary to record the durable power of attorney at the Clerk's office in your county courthouse if your agent has to act on your behalf. This would only need to be done at the time your agent needed to act. If you become ill, your agent will be able to manage your financial affairs. There should be no need for you to be declared incompetent or to have a Guardian appointed.

The power granted to your agent may be extremely broad. The person selected should be trustworthy. We recommend that you name an additional agent in case your first choice is unable or unwilling to act.

Additionally, major changes were made in the Power of Attorney Statute in Florida in October, 2011 which requires a review of all Powers of Attorney and may require updating. Now, certain powers must be specifically listed in the document and particularly authorized or your agent will not be able to take those acts on your behalf.

DECLARATION OF PRE-NEED GUARDIAN

You may designate your preference for a personal guardian, should the need arise, rather than the court appointing a stranger from a list of qualified Guardians.

Last Will and Testament

In the Last Will and Testament is where we appoint guardians for minor children and also where we can incorporate trusts for minors and individuals with special needs. Consider having responsible individuals in charge of inheritances and when public benefits are present, or in the future, a purely discretionary trust is likely advisable. For the children or heirs with no special needs, minimum ages are usually necessary before allowing the beneficiary to direct the full use of the inheritance. For individuals who are incapable of managing money or who are dependent on means-tested public assistance programs such as Supplemental Security Income or Medicaid, a Special Needs Trust should be incorporated.

Guardianship

What about that Guardianship? All minors need guardians which are usually the parents or another family member. When the child becomes an adult a stockpile of civil rights suddenly (and automatically) transfer from the guardian to the new adult. These rights may vary a little from state to state but likely include: Enter into and perform contracts, make medical decisions, apply for governmental benefits, determine residency, determine social environment, handle finances or sue and defend lawsuits. Other rights may also be addressed as needed like the right to travel or certain major medical decisions. The rights to vote, drive, work and marry may also be addressed. Generally we want to find the least restrictive alternatives to appropriately balance the protection of the vulnerable person with the autonomy and dignity that goes along with making our own decisions and the ability to take acceptable risks and even sometimes fail. These decisions will be made in a court process that will be very personalized for the unique family member.

Special Needs Trusts

What about the money? There are many different ways to establish a Special Needs Trust (SNT) for an individual with special needs. Sometimes the SNT is embedded into a Last Will and Testament and then when the will is probated the SNT is established and funded. This is called a testamentary trust. The downside with this type of trust is that it does not come in existence until the death of the Testator and thus cannot be funded with other funds until then, and it must be established through a court process of probating the will. We can avoid the probate process by embedding the SNT within a typical revocable family trust that is still set aside and funded upon the death of the trust's Settlor.

If other family members or friends may want to leave some funds to the individual with special needs, a testamentary trust may not be timely enough. We may want a SNT to be in existence now so we can made it as easy as possible for the other family members and friends to leave funds to our loved one. Once this SNT is established we can adjust existing estate plans, including will and trusts, as well as beneficiary designations to direct funds into this SNT for the benefit of our loved one with special needs. Generally these types of SNT's would be irrevocable in order to provide the protections needed for the beneficiary but sometimes they may be drafted to still be amendable or revocable by the

Settlors until someone other than the Settlors fund the trusts. The need for creditor protection and tax planning factor into whether these trusts start out as irrevocable or revocable.

Here is an overview of Special Needs Trusts in a short handout:

> Planning an estate is never an easy task. When a family member has a disability, most parents are lost as to where to begin. Many disabled individuals are entitled to public benefits that provide income for living and medical expenses. Many times the medical expenses are substantial. Programs such as Supplemental Security Income (SSI) and Medicaid are designed for individuals with minimal financial resources. A simple Will leaving the family savings to the children can cause a disabled child (adult or minor) to lose much needed public benefits. Yet, in many families the disabled child is the primary concern of the parents. **Don't just disinherit your child**.
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> The public perception of children with disabilities has changed dramatically over the past twenty-five years. With changed attitudes and advances in medical technology, the life expectancies of persons with disabilities have come more in line with those individuals without disabilities. Many disabled adults are outliving their parents which can cause serious concerns regarding who will provide much needed care for the child with a disability. Another major concern is how to preserve assets for the child with a disability without jeopardizing public benefits.
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> Many parents are not aware that special planning tools are available to protect assets and governmental benefits. A **Special Needs Trust** (SNT) is a trust designed specifically to provide funds for a disabled individual's needs without putting their public benefits at risk. Parents can establish these trusts during life or through testamentary plans.
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> SNT's are used to shelter funds for the benefit of the person with a disability. These funds are typically the result of an inheritance or personal injury award but can come from any source. Funds are available for anything **not** provided by public benefits. Within a properly drafted trust the funds are not considered in determining eligibility for public benefits.

EXAMPLE 1 – 3rd Party SNT

> Maria is living in a group home (or in her own apartment) and receiving Supplemental Security Income (SSI) and Medicaid. Maria's parents have always provided for Maria's needs that were not met by her public benefits. Maria's parents want to ensure that Maria will have money for her lifetime for any needs that may arise. Maria's parents incorporate a SNT for Maria in their existing estate plan. Maria's parents appoint Maria's brother as the Trustee to use the money for anything not covered by SSI or Medicaid. Maria maintains her eligibility for public

benefits and a reserve fund is thus made available to provide for enhanced care and to add to Maria's quality of life. Any funds remaining in the SNT at Maria's death will go to her siblings or nieces and nephews.

EXAMPLE 2 – Under Age 65 SNT

Several years ago Mark was injured in an accident and is now permanently disabled. The personal injury lawsuit that has been pending since the accident is about to be settled for several hundred thousand dollars. Mark has been on public benefits since the accident. If Mark receives the settlement in a lump sum he will lose his public benefits. Instead, Mark will establish a SNT to receive the settlement. The funds will be held in the Trust to provide additional benefits for Mark until he dies. With this type of SNT, upon his death, the State of Florida will be repaid from the SNT for the benefits paid on Mark's behalf during his lifetime. Any funds remaining in the trust after reimbursing the State will pass to Mark's heirs.

These are just two possible examples of how specialized estate planning can maintain much needed public benefits for individuals with disabilities. Otherwise an inheritance or personal injury settlement will be quickly depleted and no funds will be available to provide for extra care.

Many parents believe they can address these problems by leaving their entire estate to other children, or family members who are not disabled, with mere instructions to use the money for the child with a disability. There are many problems with this plan. For instance, the non-disabled child could: (1) predecease the disabled child, (2) get divorced and lose funds to their ex-spouse, (3) get sued, or (4) have creditor problems. Any of these examples could cause the funds to not be there for the disabled child.

Finally, proper estate planning includes not only planning for others after your death, but planning for yourself during your lifetime. You must plan for the possibility that you, as the caregiver of a family member with a disability, could yourself become disabled. You must be certain that your estate will be preserved for your family, particularly your loved one with a disability. This includes working with a skilled attorney to discuss taxes, creditors, probate and nursing home coverage.

Just having the correct legal documents isn't enough. Coordinating the financial plan, including titling of assets and accounts, as well as the beneficiary designations, is critical in fulfilling the estate plan. Parents are often confused about how to fill in the beneficiary forms for their life insurance and retirement plans. Naming the special needs beneficiary directly as beneficiary on these investments is the wrong answer. Also, we don't want to just completely disinherit our special needs family member either and just leave the other kids as the sole beneficiaries. If we disinherit a beneficiary we are then leaving it up the designated beneficiaries to do the job we should have done and properly protect our loved one. Using the SNT we can still have the right parties in charge of the funds, but not have

the funds includable in the trustee's personal funds in the event of a lawsuit, divorce or death of the trustee. We would name back-up, or successor, Trustees to take over in the even our first choice became unwilling or unable.

As compliments to SNT's we now have ABLE accounts. The Achieving a Better Life Experience (ABLE) Act allows individuals with disabilities and their family and friends to deposit funds into, and thus maintain funds in, an ABLE account, while maintaining government benefits.

ABLE accounts are not trusts but can be very helpful and a powerful tool for certain individuals with disabilities. To use an ABLE account the disability must have occurred prior to age 26, so the eligible candidates will be limited. Annual contributions will be limited and some states subject ABLE accounts to Medicaid recovery upon the death of the beneficiary. The ABLE account grows tax free provided the funds are used for qualified disability expenses.

Qualified Disability Expenses include:
Education, housing, transportation, employment training and support, assistive technology and related services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for ABLE account oversight and monitoring, funeral and burial, and basic living expenses, and anything added by Secretary of the Treasury.

Recent changes to ABLE law include the ability to roll 529 plans into ABLE accounts, contribute earnings into ABLE accounts up to $14,580 per year (this may vary by state) on top of the current annual limit of $17,000 and eliminating direct claims on ABLE accounts for Medicaid recovery, but rather rolling the remaining funds to the estate of the beneficiary.

Next, coordinating the titling of the assets of our clients and likewise coordinating the proper beneficiary designation on assets such as life insurance, retirement plans and annuities are all necessary steps. Too often improperly titling assets jointly with others or failing to properly designate beneficiary designations ends up frustrating the best drafted estate plans. Our clients need to realize that trusts only control assets that have been retitled into the name of the trustee on behalf of the trust or that flow into the trust as the result of person's death (through a will or a beneficiary designation). Similarly, a person's Will only controls an asset upon death if there is no living joint owner or there is no beneficiary properly designated. We need to coordinate the financial accounts with the legal plan. We will often be working the client's financial advisor and accountant on titling issues and beneficiary designations.

Finally, who better to tell the story of a child with special needs than the parents. Legal documents can only go so far in addressing the myriad of little things to know about a beneficiary with special needs. Letters or Memorandums of Intent can help to fill in the many gaps in information about a person. These "Letters" can take many forms and there is no right or wrong way to prepare one. They cover such wide ranging topics as medications and past medical history to what kind of cereal a person likes. Parents and guardians can express individuals they would like to be in their loved one's life and those

they do not. Habits, preferences, routines, likes and dislikes can be made known. A Letter can explain what benefits a person receives and how these benefits have been used in the past. A Letter may include past educational information and future goals. There are many samples and examples of these Letters with resources available through the Academy of Special Needs Planners.