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Estate Planning for Families with Special Needs Children

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.

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.

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.

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.

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

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 to 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 event 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.

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 and other similar organizations.