

The Voice, *The Official Newsletter of SNA*

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Welcome!

You are reading *The Voice*, the e-mail newsletter of The Special Needs Alliance. This installment was written by Special Needs Alliance member [Hyman G. Darling](#) of Springfield, Massachusetts. Mr. Darling is a shareholder in the law firm of [Bacon & Wilson, P.C.](#) His practice is primarily focused on estate planning, particularly planning for families including a member with a disability. Mr. Darling also lectures and writes on estate planning topics extensively, and is very active in his local community. He is certified by the [National Elder Law Foundation](#) as a Certified Elder Law Attorney.

Planning Your Estate: When a "Simple Will" Won't Suffice



Introduction: Parents of a child with a disability face many challenges, but none is more pressing than their concern about what will happen to their child on their death or incapacity. Because parents have a difficult time making these decisions, procrastination and avoidance may result. Too often, nothing gets done until very late in life.

It has been estimated that there are over 700,000 American adults with disabilities who have living parents over age sixty. This highlights the often unmet need for people to plan in advance.

Getting Started: Sometimes the problem of inertia is heightened by parents' concern about getting the plan "right" the first time. Once a plan is initially prepared, it is usually easy to make changes or amendments as times, needs and understanding change. For instance, the selection of a guardian for a minor child might favor grandparents, uncles or aunts. As time goes on and family dynamics change, the child's brothers and sisters may be more logical choices. It may even be advisable to allow the decision about caretakers to shift from one generation to the next as the child's siblings become mature, responsible and ready to take on the future needs of the child with a disability.

Elements of the Plan: In preparing the plan, the usual documents should be completed including advance directives (sometimes called a "health care proxy" or "health proxy") a will, and a financial power of attorney for the caretaker parent. While most people prefer simplicity in their documents, when there is a child with a disability a "simple" will may not be sufficient to provide for that child's needs. There should be a comprehensive plan to provide for those needs; it will probably include a "special needs trust."

A special needs trust has a two-fold purpose -- providing for management of assets for the beneficiary while protecting the beneficiary's eligibility for means-tested government benefits. To the extent that medical care, food, shelter, etc. are not otherwise provided, the trust can even help to ensure coverage for basic needs.

The funds in a special needs trust are usually available for "luxuries" (as opposed to necessities) during the beneficiary's lifetime. These luxuries might include vacations, companions, televisions, or massage therapy, just to name a few.

As part of the planning process, the parents should consider the potential for public benefits in the future to ensure that they are not lost. This may include Supplemental Security Income (SSI), food stamps, housing, fuel assistance, and possibly other resources. Most parents, however, would want to go further: if the availability of public or other benefits was ever diminished in the future, most would hope that the money in the trust would be available to provide for even basic necessities. With proper planning before death or incapacity, parents can include such provisions.

What Else Do You Need? Parents of a child with a disability should also be thinking about another important planning instrument: a care plan (some practitioners refer to a "letter of instructions") established by the family to make the guardian and trustee aware of the child's needs. This care plan should be updated every year, and a copy kept with the trust and other planning documents. A good, current care plan will describe the educational, social, financial, and other issues faced by the child with a disability. It will also describe the child's needs, and his or her ability to attend to those needs on a daily basis. Any special and even basic information should be included, with information that will be helpful to the trustee and guardian when considering the beneficiary's housing and social situation, as well as the family's hopes and wishes for the beneficiary's transition from minority to majority and adulthood.

As an additional benefit, proper preparation and "funding" of a trust during a parent's lifetime may help avoid the probate process upon the death of the parents making the plan. During the planning process there may even be an opportunity to minimize or eliminate state or federal estate taxes, and in some cases even to help plan for the parents' own future long-term care needs. In other words, the planning for a family which includes a child with disabilities can be much more complicated than for other families. A "simple" plan may not suffice, but the opportunity to make a real difference in the life and future of the child with disabilities should motivate parents to plan, carefully and early.

Use Qualified Professionals: It is important to contact professionals knowledgeable in this area as the rules are both complex and fluid. Services vary by state and often by region, and programs in place today may not exist, or may be quite different, next year.

The trustee and guardian must be armed with information and strategies, as well. The details of the administration and taxation of the Special Needs Trust can be quite involved, and a qualified professional should be consulted to assist in that process. One of the best sources to locate this type of attorney is through the Special Needs Alliance. Alliance members are selected by invitation, and the group includes many of the most experienced practitioners across the country. These attorneys are recognized by their peers for their competence, caring

and their expertise in preparing plans for disabled families.

About this Newsletter: We hope you find this newsletter useful and informative, but it is not the same as legal counsel. A free newsletter is ultimately worth everything it costs you; you rely on it at your own risk. Good legal advice includes a review of all of the facts of your situation, including many that may at first blush seem to you not to matter. The plan it generates is sensitive to your goals and wishes while taking into account a whole panoply of laws, rules and practices, many not published. That is what The Special Needs Alliance is all about. Contact information for a member in your state may be obtained by calling toll-free (877) 572-8472, or by visiting www.specialneedsalliance.com.