

Planning Your Estate: When a “Simple Will” Won’t Suffice

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FAST FACTS

- Over 700,000 American adults with disabilities have parents age 60 and over.
- A special needs plan may be modified as needs change.
- A special needs trust manages assets while protecting eligibility for government benefits.
- A care plan ensures that a future guardian and trustee will be aware of the child’s needs.

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 in the event of 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. Estate planning for a family that 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 a disabled child should motivate parents to plan carefully and early.

It has been estimated that there are over 700,000 American adults with disabilities who have living parents over age 60. This highlights the often unmet need for people to plan in advance.

Getting Started

Sometimes the problem of inertia is heightened by the parents’ concern about getting the plan “right” the first time. Once a plan is prepared initially, 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 the 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 durable power of attorney for the caretaker parent. While most people prefer simplicity in their documents, when there is a child with a disability in the mix, 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, and 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, and shelter 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, to name a few.

As part of the planning process, parents of a special needs child 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, 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 (also called a “letter of instructions”) established by the family to make a future guardian and trustee aware of the child’s needs. This care plan should be updated every year, and a copy should

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About the Author



Attorney Hyman G. Darling is Chairman of Bacon Wilson, PC’s Estate Planning and Elder Law Departments, and he is recognized as the area’s preeminent estate planner. His areas of expertise

include all areas of estate planning, probate, and elder law. Darling is a past President of the Hampden County Bar Association; he teaches elder law at Bay Path College and is an Adjunct Professor at Western New England College School of Law (the LLM program) where he teaches elder law. He is a frequent lecturer on various estate planning and elder law topics at both the local and national levels, and he hosts a popular estate planning blog at http://bwlaw.blogs.com/estate_planning_bits.

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CME (cont.)

Fee: \$175 (Physicians); \$125 (Others)

Details: This course will train health care providers to identify susceptible populations, help prevent addiction, and treat addicted patients.

Credit Info: 11.0 AMA PRA Category 1 Credit(s); 11.0 CASAC hours

Date: November 17–21, 2008

Name of Course: Current Concepts in Surgical Pathology, 30th Annual Course

Location: Four Seasons Hotel, 200 Boylston Street, Boston, MA

Professions Impacted: Pathology

Director(s): Judith A. Ferry, MD, Eugene J. Mark, MD, Andrew E. Rosenberg, MD, and Robert H. Young, MD

Contact: Harvard Medical School CME by phone: 617-384-8600 or e-mail: hms-cme@hms.harvard.edu

Fee: \$1250 (Physicians); \$850 (Residents/Fellows/Allied Health Professionals)

Details: The objective of this course is to improve the skills of surgical pathologists by focusing on new information and techniques relevant to their practice and emphasizing problems likely to be encountered in a busy practice.

Credit Info: Course only: 35.25 AMA PRA Category 1 Credit(s); course with study session, 36 AMA PRA Category 1 Credit(s); course with evening seminar, 36.75 AMA PRA Category 1 Credit(s); and course with study session and evening seminar, 37.5 AMA PRA Category 1 Credit(s)

Date: November 19, 2008

Name of Course: 24th Ella Grasso Memorial Conference, OB/GYN: Division of Gynecologic Oncology

Location: The Anlyan Center for Medical Research and Education, 300 Cedar Street, New Haven, CT

Professions Impacted: Obstetrics, gynecology, reproductive medicine, radiology, and oncology

Director(s): Peter E. Schwartz, MD

Contact: Yale CME by phone: 203-785-4578 or e-mail: cme@yale.edu

Fee: \$150 (Physicians); \$50 (Nurses/PA/Residents/Fellows)

Details: This course will provide an update on the early detection of ovarian cancer, focusing on a proteomic approach, the most sensitive and specific test for diagnosing the presence of ovarian cancer.

Credit Info: 5 AMA PRA Category 1 Credits

Date: November 21–22, 2008

Name of Course: Treating Couples

Location: Boston Park Plaza Hotel, 64 Arlington Street, Boston, MA

Professions Impacted: Counseling, social work, psychology, psychiatry, nursing, and family therapy

Director(s): Jill Elka Hardaway, Judy Reiner Platt, and David C. Treadway

Contact: Cambridge Health Alliance Physicians Organization by phone: 617-503-8445 or e-mail: cme@challiance.org

Fee: \$350 (Physicians); \$275 (Others)

Details: Participants in this course will improve their knowledge of couples work by learning how to help reduce tensions between love, sex, and intimacy; facilitate change in failing marriages; work with couples facing physical and emotional challenges; foster compassion; confront secrets; accept apologies; and apply different therapeutic approaches.

Credit Info: 14 AMA PRA Category 1 Credit(s); 14 CE credits for psychologists, counselors, educators, social workers, and family therapists; 16.8 hours for nurses.

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be kept with the trust and other planning documents. A good, current care plan describes the educational, social, financial, and other issues faced by the disabled child. It also describes 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, as well as information that will be helpful to the trustee and guardian when considering the beneficiary's housing and social situation. In addition, it is a good idea to include information about 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 the parents' lifetime may help to avoid the probate process upon the death of the parents. 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.

Use Qualified Professionals

It is important to contact professionals who are 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 families with a disabled child. Contact information for a member in your state may be obtained by calling toll-free 877-572-8472 or by visiting www.specialneedsalliance.com. ■