

## **SPECIAL NEEDS TRUST PLANNING IS A MARATHON, NOT A SPRINT**

*by Karen H. Weber, Elder Law and Special Needs Lawyer*

One of the greatest fears a parent has is that she might die without having identified a caregiver for a son or daughter with disabilities. While many parents find themselves touring college campuses when a child reaches age 18, the parents of children with special needs find themselves meeting with a lawyer to discuss the concepts of durable power of attorney documents versus court-ordered guardianship. In some cases, the 18-year-old with disabilities is able to sign his own estate planning and financial decision-making. In other cases, the 18-year-old with disabilities lacks the legal capacity to execute such documents and court-ordered guardianship and conservatorship may be necessary. Housing arrangements, employment training, and preparing for independence all take years of planning and must be coordinated with applying for government benefits. The special needs lawyer provides all these services because her focus is on the long-term health and well-being of the client and not just the immediate short-term issue.

For example, once a family establishes guardianship, special needs planning continues. The guardian will need assistance filing annual reports and accountings, and this can continue for years. Court authorization is also required if the person with disabilities transitions to certain types of care facilities.

The special needs lawyer is there to assist each step of the way. The special needs lawyer will also assist the family in determining whether the person qualifies for government benefits such as Supplemental Security Income (SSI), Social Security Disability Insurance, or Medicaid. Each of these government programs have their own set of rules and regulations, and the special needs lawyer is dedicated to staying abreast of the ever-changing landscape of these rules and regulations.

An adult with a disability may remain dependent upon his parents or other family members for housing and supervision. This type of family support often allows the person with disability to remain in the community rather than a facility. Families must consider how these support services will continue to be provided when they are no longer alive. If a parent dies without planning for the continuation of these services, the quality of life for the person with special needs is likely to be significantly affected. It is never too early or too late to start planning for long-term care of a person with special needs.

Parents can become familiar with programs and agencies that offer support and services to determine what private resources will be needed to supplement the services provided by government programs. With proper advice, the future care of the person with special needs can be integrated into the long-term estate plan of the family. One of the best tools available to meet the long-term care of a loved one with a disability is the special needs trust, also known as a supplemental needs trust.

A supplemental needs trust is a special kind of trust that holds assets for the benefit of a person with a disability so that the trust assets are not directly available to the trust beneficiary. Since the trust assets are not directly available to the beneficiary, governmental benefits such as SSI and Medicaid are preserved while the trust beneficiary has a source of funds available for services, recreation, and therapies that are "supplemental" to the basic support of food and shelter provided by governmental programs. Distributions from the supplemental needs trust can be created during life or at the death of the parent. With the use of a supplemental needs trust, parents do not need to disinherit a child with special needs and they can identify a successor caregiver for the long-run.

*Karen H. Weber has been practicing law for over 25 years, and she has been a member of the National Academy of Elder Law Attorneys, Inc. (NEALA) since 1996. Her practice is devoted to estate planning (including will, trusts, powers of attorney, etc.), with an emphasis on elder law (including Medicaid qualification for assisted living and nursing home care) and special needs law (including guardianship and special needs trusts). Karen Weber can be contacted by calling 913-661-0550 or emailing at khweber@elderlawkc.com.*