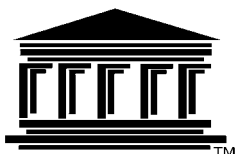


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## CARE MANAGEMENT SERVICES FOR PEOPLE WITH DISABILITIES AND MENTAL ILLNESS: A GROWING NEED

BY  
ANNE MCNIFF

As the families of individuals with special needs undertake long-term financial and estate planning, they face critical challenges and require professional assistance. Attorneys, trust officers, and other estate planners, however, know that financial planning is only one part of what needs to be determined. Questions, such as, "Who will take care of my family member with special needs after I am gone?" and "Who will make sure that my family member with special needs continues to have the highest quality of life possible?" will be raised and need to be answered.

Parents, siblings and relatives who have a family member with a mental, developmental or physical disability frequently have the ongoing responsibility for their care and support, far beyond that ordinarily required. This greatly impacts the planning process. Primary concerns are the provision of a safe, secure environment and the level of support and oversight needed to assure that those with special needs have a high quality of life long after family members are able to provide it. The increase of people with disabilities who live on their own or in supported living situations has contributed to the concern of many families about the assurance of appropriate long-term care.

Trust officers and conservators/guardians, who are usually the ones with the fiduciary responsibility for a person with special needs after the parents have

died, often freely admit to their understandable lack of expertise in defining and providing the complex services required by an individual with life long special needs and in the management of public benefits. Siblings may be equally bewildered by these demands, and they frequently live far away.

Care management services provide oversight and expertise, including the individual advocacy and oversight essential for assuring the highest quality of life for persons with special needs. The concept of care management is based on the need for an array of services that evaluates, plans, coordinates, monitors and advocates for whatever services and supports are needed. For individuals with special needs, these services differ from typical care management services, often provided for the elderly, because they are provided by those with experience and training in addressing the complicated needs of individuals with a developmental, physical or intellectual disability, or a mental illness. There is a growing need for this type of service, and the impact on professionals that provide services (financial, legal and advisory) to families that fall into these categories is undeniable:

- The number of persons over age 65 will double over the next 30 years (US Census Bureau, 2002) greatly impacting those individuals who currently receive care at home.
- The pool of family caregivers is dwindling. In 1990 there were 10 potential care givers for each person needing care. In 2050 the ratio will be 4:1.
- Nearly 27% of the adult population has provided care for a chronically ill, disabled or aged family member or friend in the past year.
- In 2002, approximately 2.79 million of the 4.56 million individuals with developmental disabilities in the United States were receiving residential care from family caregivers, and an estimated 708,000 (25%) of these caregivers were over age 60.
- Between the 1970's and the mid-1990's, the mean life expectancy for individuals with developmental disabilities increased from 59 to 66 years. It is anticipated that people with developmental disabilities, particularly those without the most severe impairments, will soon have a lifespan equal to that of the general population.
- In 2000, an estimated 641,000 adults age 60 and older had been diagnosed with mental retardation and other developmental disabilities; this number will double by 2030.

Families have strong preferences regarding the future care of their family members, but less than one half of these families actually develops a plan for the future. Families often do not involve siblings in planning, even though it is a sibling that most commonly takes over the responsibility for a family member with special needs. Through a single coordinated approach, care management services for people with special needs are designed to provide services such as:

- Clinical assessments and evaluations;
- Program and healthcare monitoring;
- Consultation and coordination with professional caregivers;
- Referrals to appropriate service providers and community resources (when needed);
- Regular client, caregiver and family communication;
- Assistance in managing public benefits; and
- Coordination with financial services partners, estate planners, attorneys, and others.

Oast & Hook assists its clients in obtaining care management services for family members with special needs, and Oast & Hook considers care management services part of an integrated approach to long-term care planning. For assistance with these issues, please call Oast & Hook at 757-399-7506. For more information about Anne McNiff and Devereux Life Management Services, please email Ms. McNiff at [AMCNIFF@devereux.org](mailto:AMCNIFF@devereux.org), call 610-542-4476, or visit Devereux Life Management's website at [www.devereuxlifemanagement.org](http://www.devereuxlifemanagement.org).

*Anne McNiff is the director of the non-profit Devereux Life Management Services program. Founded in 1912, and headquartered in Villanova, Pennsylvania, Devereux is the nation's largest, independent, non-profit provider of services to individuals who face a wide range of intellectual, behavioral, and neurological challenges.*

### **Seminar**

Oast & Hook is proud to present a seminar entitled: "Recent Developments in Long-term Care Planning." This seminar is open to the public, and it will be held at the Chesapeake Conference Center, 900 Greenbrier Circle, Chesapeake, Virginia 23320, from 9:00 a.m. to 11:00 a.m., Monday, January 23, 2006. For more information, please telephone Jennifer Lantz or Linda Gerber at 757-399-7506.

### **Distribution of This Newsletter**

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