

The Voice, *The Official Newsletter of SNA*

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Welcome!

You are reading *The Voice*, a newsletter published by The Special Needs Alliance. Our purpose is to provide information--and answers--about special needs planning for family members and professionals. We hope this newsletter helps you. We invite your questions, suggestions and comments (please understand that we can not give individualized legal advice on the basis of an e-mail inquiry). We also encourage you to forward our newsletter to others who might benefit from the information here, or who might have similar questions.

Managing Care: A Looming Perfect Storm



Introduction: Those of us in the disability advocacy community face a looming "perfect storm": caregivers are aging, funding cuts continue, and the agencies that administer the public entitlement system are becoming more rigid in their oversight and enforcement. These all combine to raise the bar for those who currently provide care and oversight of family members with disabilities, as well as those who will eventually step in when current family caregivers can no longer do so.

What Does the Storm Look Like? Consider these demographics:

- The number of persons over age 65 will double over the next 30 years (U.S. Census Bureau, 2002). Many of these individuals are parents and other caregivers for individuals with disabilities, and some of them (and others who are not caregivers) will require family care themselves.
- Even as the need grows, the pool of family caregivers is dwindling. In 1990 there were 10 potential caregivers 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 1970s and the mid-1990s, 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 with less 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.

It is vitally important to document the needs, preferences and other information concerning a family member with a disability. As the current generation of primary caregivers (usually parents) age they need to arrange for the transition of care, oversight and advocacy roles to those individuals and organizations who will follow them: siblings, other family members and friends, and in some cases, the voluntary agencies that serve the disability community. This documentation is often accomplished through a "Letter of Intent" or "Life Care Plan" written by the parents or current caregivers. This information supplements what might be officially available through an Individualized Service Plan (ISP) or other information maintained by a provider agency, and will be of tremendous importance to those successors who assume oversight and advocacy roles in the future.

Are Resources Already in Place? It is also prudent to remember two very important limitations. First, successor caregivers and advocates (be they siblings, friends or agencies) can rarely replace the time, effort and energy that parents have dedicated to their sons and daughters with disabilities. They have lives of their own, and in many cases live in other areas of the state or country. Second, the "perfect storm" we mention above will also strain the resources of the voluntary agencies that many are relying on to "fill the gaps" left by aging and deceased parents and caregivers. Just when the need is increasing, the process of obtaining entitlement eligibility is becoming more contentious and, in some cases, the programs and services themselves are being cut or limited.

These two limitations give rise to what we believe will be a growing need: the need for private advocates, care managers and other assistants who will work together with the next generation of family caregivers to carry on where parents have left off. Our readers know about "Special Needs Trusts," understanding that they represent a private source of funds to supplement what might otherwise be available through the government safety net. The discussion of trusts often focuses on entertainment and other quality of life expenses. What the demographics at the outset of this article suggest to us is that these trusts also need to become a source of funds to provide, on a privately paid basis, critical assistance and oversight beyond what siblings, other family members, and voluntary agencies will be able to provide after the death or disability of caregiver parents.

What Role Can Private Care Managers Fill? The type and level of services will vary depending on the nature of the disability, the primary entitlement programs supporting the person with the disability, and other case-specific factors. But the list of potential services can be quite expansive:

- Clinical assessments and evaluations;
- Health care monitoring;
- Oversight and advocacy in connection with the services provided by the primary disability service provider (we often call this "watching the watchers");
- Referrals to other appropriate service providers and community resources (when needed), and follow up to ensure that referrals are acted upon;
- Regular communication with caregivers and family members residing out of the area;
- Assistance in managing public benefits; and
- Coordination with financial services partners, attorneys and others.

For someone residing in a community residence with 24 hour supervision, many of these services will be provided by the certified agency. In most cases there will be a service coordinator or care manager who will have the responsibility of providing oversight, supervision and advocacy. Yet many individuals with disabilities will live in independent community based settings with less monitoring and oversight. Every parent, caregiver and advocate for those with disabilities must be honest and admit that staff turnover continues to be a problem even in the most efficiently run organizations. In our view, having a privately hired and paid advocate can be essential, if for no other reason than to ensure that there is always a set of eyes and ears that can report to siblings and other family members who will step in when the parents are gone.

A Word of Caution. As we have said, this will be a growing need. Right now this model exists primarily in the geriatric care community. In this situation, advocates (such as members of the [National Association of Professional Geriatric Care Managers](#)) are hired, often by sons and daughters living out of the area, to supervise and oversee the care that is being provided to their elderly parents -- whether in a home based or nursing home setting. We think that many existing disability service providers can fill this role for the younger disabled, although in our experience these providers are generally less comfortable with the "private pay" model, since most of them have long operated primarily as contractors for government programs.

As the private care manager model develops, whether by expansion of existing elder care programs or development of private-pay versions of existing contractors, these oversight and advocacy functions will often be filled by private social workers, and in some cases by non-professionals. At this point none of those organizations or individuals are regulated by any agency and there is no established professional organization specifically dedicated to this cause. So for those clients who enter this arena, we recommend that they hire cautiously, ensure that the "arrangement" is reviewed by a lawyer familiar with fiduciary oversight and entitlement program eligibility, and that there is a protocol and legal infrastructure for terminating the relationship, with or without cause, if it does not work as well as one may have expected.

Individual members of the Special Needs Alliance across the country are slowly accumulating information about individuals and agencies that have been providing these services already, or who are interested in pursuing the private caregiver model, in local community settings. Many of us have also acted as "Trust Protector" for clients who lack family members to fill this role. We continue to encourage existing disability service providers to consider this growing need. As parents pass on and as Special Needs Trusts are funded (and as courts appoint Guardians and Conservators) over the next few years, we expect to counsel more and more of our clients to consider the need and effectiveness of these arrangements.

About the Author: [Edward V. Wilcenski](#) is an attorney with Jones & Wilcenski, practicing in Clifton Park, New York (just north of Albany). He has written and lectured extensively on special needs planning and elder law issues, and recently completed a one-year term as President of the [Special Needs Alliance](#). He is a Trustee of the [NYSARC Pooled Trust](#), and has been actively involved in the disability advocacy community since beginning his law practice. Mr. Wilcenski is the proud brother of a developmentally disabled man.



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