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Managing Care for the Disabled Child: The Private Care Manager

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.

Are Resources Already in Place? It is 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. (See “Third Party Special Needs Trusts for Disabled Children” on the Articles page of our website.)

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.

Our Care Management Resource. If you need a private care manager who can oversee and coordinate care for a disabled child or adult, our Certified Care Manager may fit the bill.

Leigh Leverette, CMC, is a member of the National Association of Professional Geriatric Care Managers and was previously employed as a Medicaid services coordinator with the Mississippi Department of Mental Health. She is able to identify care resources and work with family members to obtain such resources. She can also educate caregivers to become better personal overseers and advocates for their children with special needs. **Call Leigh at 601-987-3000 or toll-free at 866-353-3752 to discuss how she may assist you with care management.**