Care Managers and How They Support Individuals with Disabilities

This issue of The Voice® was written by SNA member Kristen M. Lewis of Harrison, LLP in Atlanta, Georgia. Her firm focuses on special needs, estate and trust administration, guardianship and conservatorship, and estate planning.

A professional care manager may be the most valuable – yet least recognized – member of a family's team of allied professionals. Until a family needs a care manager for the first time, they have no idea how wide-ranging the skills of a care manager can be to support a person with a disability. Because a special needs plan is not self-implementing, it can be very helpful to have a care manager as one of the first members of a family's team of allied professionals consulted in designing and implementing their special needs plan.

Care managers come to the team with differing backgrounds: some are social workers, some are medical physicians or physician's assistants, and some have nursing credentials. (I have most frequently worked with nurse care managers.) Some families have used a geriatric care manager to facilitate long-term care planning for an elder needing a skilled nursing facility. Increasingly, Care Management firms are designating their staff as disability care managers (DCM) trained to work with individuals who are not considered seniors but whose disabling conditions necessitate similar planning (both current and future) as a part of comprehensive special needs planning.

In-Home Assessments Are the First Step

Inasmuch as a care manager cannot operate in a vacuum, a care management engagement typically begins with a comprehensive in-home assessment of the individual's existing residential and care arrangements, with input from members of the individual's support network and team of allied professionals. A care manager typically will request that the individual (or representative) execute a services agreement and remit a small initial retainer. Care management services are generally rendered at an hourly rate rather than as a flat fee.

Services include those that address the individual's myriad needs: health care, emotional, functional, legal, financial, residential, and support. Care managers are problem solvers, advocates, service coordinators, and counselors with a deep knowledge of the resources available in the individual's community. They excel when retained early in the process but are equally effective in crisis situations. They can work with an individual's local team of allied professionals and with long-distance family and team members. While care

managers do not typically provide hands-on support services - such as those rendered by a direct support professional (DSP) - they coordinate direct service and support professionals in collaboration with the other members of the individual's team.

Identifying DSPs is a critical role of a care manager. In an economic environment where the need for DSPs far exceeds their availability, care managers are often part of a local network with insider knowledge of available DSPs. The care manager knows which DSPs are wrapping up an engagement due to the impending death or relocation of an individual and which families need the services of those DSPs. Such inside information enables the DSP to be re-engaged to assist another individual without missing a single day of employment.

Care managers excel in identifying DSPs with specialty skills and often are tasked with assembling teams of DSPs with complementary skills to support individuals with complex medical needs. Such medically complex individuals often require several shifts of specially trained DSPs. Care managers are also ideally suited to identify live-in DSPs for short-term or long-term engagements. Regardless of the DSP skills needed, care managers often can train (or retrain) and monitor the DSPs and facilitate the hiring and termination of staff. They are integral to developing an initial care plan for an individual and modifying the plan as the needs and circumstances of the individual warrant.

In the context of crisis intervention, a care manager expertly assists an individual (and family and team) to navigate care transitions: from an emergency department to in-patient hospitalization, to rehabilitation, to in-home care. Since many care managers have medical and nursing backgrounds, they are considered peers by the providers rendering care in each of these settings, while family members often struggle with "medical mumbo-jumbo" and "run-around" tactics from those same providers. Care managers can ensure that the care rendered in each setting is adequate, appropriate, and available to the individual when family members have not succeeded. For families who live a long distance from an individual being supported locally, care managers serve as around-the-clock liaisons to the individual and the rest of the team.

Working Miracles

Care managers have worked miracles for my clients! In two recent matters, a care manager was consulted in the context of a proposed emergency guardianship proceeding necessitated by the individual's erratic and threatening behaviors. The care manager's quick review of the individual's prescription drug regimen yielded a critical clue to the underlying reason for these behaviors. Once the individual's prescription drug formula was appropriately modified, the behaviors ceased, obviating the need for both emergency guardianship and permanent guardianship in each of these cases.

Care managers are also available to facilitate regular and routine health management for individuals, including rendering periodic assessments or updates and check-ins as needed. Care managers are willing to accompany an individual to medical appointments, to serve as advocates during such visits, to help the individual understand the proposed care options, and to ensure smooth and accurate communication between and among the individual, providers, and the other members of the team of allied professionals. Medication review and management is a critical service offered by care managers, especially for complex medical conditions requiring the involvement of numerous specialists. Care managers are a treasure trove of wisdom regarding hospice and palliative care options for individuals with incurable or terminal conditions who are approaching the end of life.

A care manager provides advocacy, coaching, guidance, and support for the individual, the family, and the team of allied professionals at all stages of the care management spectrum, from inception to recovery or death. If an individual's wishes, as stated in an advance directive for health care (or similar instrument), are being thwarted by a provider, a care manager can intervene to ensure that the individual's care is modified to comport with the directive. If there is no written directive, a care manager can counsel the default healthcare decision-makers regarding all available options. Increasingly, care managers serve as healthcare agents or legal guardians for individuals when they perceive that family members or friends are unwilling or unable to implement their stated healthcare wishes regarding both routine and end-of-life decisions.

Providing Guidance

Care managers are skilled in advising individuals and their families regarding placement in the various residential options appropriate for the individual's support and care needs. They know "the good, the bad, and the ugly" about local assisted living communities, memory care facilities, skilled nursing facilities, group homes, and personal care homes. Thus, families need not conduct the hours of original due diligence on these residential options (which often become a roadblock to progress for many support teams.) Care managers are also effective negotiators with these facilities' intake staff and management. They can routinely facilitate an individual's transition into or from a retirement community or a skilled nursing facility. Towards this end, care managers frequently offer residential move management services.

Move management services assist individuals and their families on a continuum that starts with developing a plan to orchestrate a move from one living arrangement to another, or with an appropriate age-in-place plan. Organizing, sorting, and disposing of furniture, furnishings, personal effects, and just plain junk (often decades in the making) cause

planning paralysis for many families. Arranging for the profitable re-homing of such accumulated items via auction, estate sale, consignment, buy-out of joint owners, and donation (or some combination of all of these techniques) can break the roadblock, allowing for a much-needed transition from an individual's current living arrangement to one that is safer and more appropriate for their required level of care.

The care manager frequently may assist the individual and family with the process of interviewing, scheduling, and overseeing professional moving and relocation services; arranging for storage of items that will not become part of the individual's new living arrangement; unpacking and setting up the individual's new residence; and related services such as cleaning, trash removal, selecting a realtor and readying a home for sale or lease.

Once an individual has relocated to the new living arrangement, a care manager can recommend appropriate in-home care and support services; develop, review, and oversee a home care plan; provide coaching for family caregivers regarding their roles under the plan; and serve as an ongoing source of encouragement and resources as they undertake their roles. The care manager is ideally suited to identify, arrange for, and monitor care staff and services. In-home staff management by a care manager often can diffuse and address volatile and emotional issues that the individual and family members cannot resolve on their own, avoiding the need to find and retrain new staff.

In short, many of my clients go from asking, "What can a care manager do for me?" to "What *can't* a care manager do for me!!" The care manager is one member of a family's team of allied professionals that they didn't know they needed, but once the care manager is retained, they cannot live without this essential team member.