



Are You Really Ready? Realistic Planning for Parents and Other Caregivers

The Voice® is the e-mail newsletter of the [Special Needs Alliance](#). This installment was written by Special Needs Alliance member [Edward Wilcenski, Esq.](#), a founding partner of the law firm of [Wilcenski & Pleat PLLC](#) in Clifton Park, New York. He practices in the areas of Special Needs Planning, Elder Law, and Trust and Estate Planning and Administration. Ed is a past President of the Special Needs Alliance and writes and lectures frequently on issues affecting individuals with disabilities and their families.

April 2021 - Vol. 15, Issue 5

At the risk of sounding trite, the coronavirus pandemic has caused many of us to consider whether we are truly prepared for the unexpected. As we read the news and experience changes in the patterns of day-to-day life, we cannot help but reflect.

When special needs planning attorneys consult with parents and other caregivers, and especially with older clients who may not be able to advocate much longer for their children with disabilities, it is important to ask whether the clients are *really ready* to discuss the transition of oversight and advocacy to their successors. In a sadly ironic twist, the pandemic has made it easier to have this difficult conversation.

To be clear, this is not a discussion about supplemental needs trusts, powers of attorney, or life and long-term care insurance. Of course those things are critically important and must be part of the conversation in the development of a comprehensive special needs estate plan. Rather, this is a broader conversation about how life will look for a child or other family member when the parent or aging caregiver is gone. These conversations are often awkward and uncomfortable, as they compel parents to acknowledge their own mortality and to assess honestly the willingness and capabilities of other family members to step into their shoes.

There is no single and simple way to approach the topic, and a full airing requires instinct, expertise, and experience. Each conversation is unique, and each solution will depend on things such as family composition, access to disability service providers, public benefits, and private resources. But all solutions will involve some combination of the three components discussed below, and understanding this will help families work through this difficult but essential part of the planning process.

Increasing Medicaid Funded Supports

The service delivery system which supports individuals with disabilities is primarily Medicaid funded, and likely will be for the foreseeable future.

Many of us have been inspired by the efforts of disability service providers during the pandemic. These “essential workers” provide communication, support and advocacy in community residences, health care facilities, and in private homes. Special needs planning attorneys understand the importance of developing estate plans to ensure continuing access to Medicaid funded staffing and other important publicly funded programs.

And yet when attorneys work with clients to develop future plans of advocacy, they must be realistic about the ability of these programs to fill the gap left when parents are no longer available. Continued political pressure to limit Medicaid expenses means less dollars available to fund programs and compensate qualified caregivers, exacerbating the problems of high staff turnover and limited access to services in outlying communities. This is not expected to change any time soon, and the financial impact on every state due to the pandemic will only put more pressure on lawmakers to reduce costs and limit services.

As such, while clients should be encouraged to pursue these programs, they must also recognize that Medicaid funded supports are only a part — and often a diminishing part — of a long-term plan of advocacy.

Utilizing Informal Supports

Some families are blessed with a deep bench. Siblings and other family members live locally and are willing and able to share the responsibilities of oversight, advocacy, and companionship that were being provided by a parent. In the author’s experience, this is the exception rather than the rule. In most cases, family members — even if they live locally — have busy professional and personal lives, and while they are willing to help, they cannot dedicate the same amount of time and attention as a parent.

The first step in assessing future supports is to have an open, honest, and realistic discussion with those family members who might be willing to step in. This is not indentured servitude, and so there is no benefit in securing promises that will go unfulfilled when the point of crisis arrives.

Fundamental to this discussion is an understanding of the different roles that family members might play. What is the difference between a trustee and a guardian? An agent under power of attorney or an agent under a health care directive? Can one person serve in two capacities? Should she? There is a lot of information about this on the internet and circulating through the grapevine, much of it incorrect (or not applicable in your state). By

understanding the requirements of each position, clients can identify which family members might be successful in certain roles.

These must be honest conversations, especially when discussing the amount of time that a family member can reasonably be expected to give. Families and their counsel need to get down to the granular level: “How many hours in a given week or month can the family member offer without sacrificing her other professional and personal commitments?” If the answer is one hour per month, then that family member should not serve as agent under power of attorney for an adult child with a disability who works, who needs his money managed, who needs his bills paid, and who needs his checkbook balanced on a regular basis.

Parents need to answer the same question: “How many hours each week do you spend advocating and providing oversight for your son or daughter?” An honest assessment will often cause parents to realize that it is unrealistic to expect a sibling or other family member to shoulder that responsibility.

These can be awkward conversations because family members do not want to disappoint or seem insensitive. In the author’s practice, attorneys will offer to speak with siblings and other family members privately and without the parent present. This allows for a more open and candid conversation, and ultimately leads to a more reliable fiduciary appointment.

Private Advocacy and Support

Understanding that Medicaid funded programs will provide a base level of services, and having identified the amount of support that can realistically be expected from siblings and other family members, one can then begin to estimate areas where privately funded, supplemental supports will be necessary. This can be an important part of the special needs estate planning process, as it helps families think about the allocation of family assets between a family member with a disability and other beneficiaries.

Some variables are easier to estimate than others. If a parent of a working adult with a disability is subsidizing the child’s rent, the parent can calculate how much might be needed over the child’s reasonable life expectancy to continue providing that level of support. Entertainment budgets and transportation subsidies are similarly easy to quantify and estimate. Circumstances can change, but this exercise is an important one as it helps families make educated guesses in the planning process.

Other variables are more difficult to predict, including the one that will likely represent the most significant expense over the life of a child with a disability: privately paid advocacy and oversight. If Medicaid funded supports will be less generous over time, and if informal support provided by siblings and other family members cannot replace the advocacy

provided by a deceased parent, then it is reasonable to expect that funds placed in a supplemental needs trust for a family member with a disability will have to be used to hire professional advocates to fill the gap.

This is not a new concept. “Life Care Plans” prepared for personal injury or medical malpractice litigation estimate the ongoing costs of care managers and related professionals when calculating damages resulting from an injury. Geriatric care professionals are regularly hired by adult children to communicate with existing care providers, supplement services, and provide a second set of eyes.

The same concept applies to advocacy for younger individuals with disabilities. The primary difference is that the cost of this advocacy has been largely hidden because parents have provided this service tirelessly and without charge, often for many decades. As parents and primary caregivers age, the need for private advocacy increases.

Something Different, But Still Something Good

The best plans of advocacy are developed when parents are still in the driver’s seat and able to guide the process, allowing siblings and other family members to participate at their own pace. Sometimes a family member is unwilling to engage at even this preliminary stage. Having that information now will allow the parent time to rethink that individual’s role in the plan.

Often, parents are pleasantly surprised to learn that family members are indeed willing and eager to help. They simply need straightforward answers about what would be expected of them.

It goes without saying that nothing can replace the tireless and uncompromising advocacy of a parent. But with good planning, frank discussions, and a recognition that government programs will only provide part of the solution, families can build a different — but otherwise successful — future plan of advocacy for a family member with a disability. As with all good planning, the hardest step is often the first one. Consider consulting a special needs attorney in your state to begin the conversation.

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