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**Special People, Special Planning:**  
**Safeguarding Family Members with M.S.**

By Peggy R. Hoyt, J.D., M.B.A. and Candace M. Pollock, J.D.

People with M.S. and their families face many challenges in their efforts to maintain independence and security in an uncertain future. M.S. people B special people -- might look to family to provide emotional, financial and personal support when needed. They might look to them to act as advocates in medical, legal or social program arenas when they are unable to do so themselves. Families might contribute resources to fill in the nooks and crannies among the government and social service programs that might be available.

But what happens when family is no longer available, due to their own disability or death, to fill these crucial roles? The confidence a special person has for their future safety and well-being is directly tied to how well they have authorized others to act on their behalf, the resources that will be available, and how these resources are used.

M.S. families are not unique in this regard. Everyone should consider "what if" scenarios for the incapacity or death of caretakers. M.S. families are unique, however, in their need to coordinate potential private and public resources to support the special person financially, medically and socially in ways that are not likely to be achieved solely by relying on one resource or the other.

Coordinating these resources doesn't happen accidentally, however. Yet, accidental estate plans are common, and not just in families with special needs. You are engaging in estate planning whether you know it or not and regardless of whether your assets are generous or modest every time you name a beneficiary on a retirement account or create a joint title on a house deed or bank account. The planning is accidental if these decisions occur without a cohesive process to make and organize them and without an understanding of their individual or aggregate consequences.

Estate planning basically boils down to creating a combination of directives to authorize others to manage your affairs when you are unable to do so, either due to incapacity or death. Wills, healthcare proxies, deeds, beneficiary forms and trusts are some of the common directives that can make up your plan. The number and type of directives can be complex or simple depending on your needs, goals and resources.

The key to good estate planning is making sure your plan is complete and understanding how each directive either supports or undermines your overall intentions. If your plan has gaps or conflicts, state laws can dictate what happens to you and your affairs. State laws rarely produce outcomes families would choose for themselves and can spell disaster for

those with special needs.

Congress has authorized safe harbors rules to permit families to coordinate private and public resources. Accidental planning and traditional planning documents are not constructed to stay within those safe harbors. Consequently, those types of plans can fail to protect special people and can directly contribute to their being found ineligible for public programs. This is why accidental planning and boilerplate, off-the-shelf estate plan documents should be avoided when planning for special people.

M.S. families have a spectrum of planning options to stay within these safe harbors rules. Stated in the most simple terms, these options must be designed to provide for the benefit of the special person without placing the assets in the individuals name or control. The most efficient mechanism to do this is through trusts. The safe harbor rules specifically authorize several types of trusts, called special needs trusts, and detail core standards regarding for whom, what and how trust assets can be used.

This does not mean the special person is at the mercy of the trust agents (called trustees) in charge of managing the trust for the special person (the beneficiary) or that their existence must be meager. The terms of the trust can be drafted to respond to the specific and changing needs of the beneficiary as long as the core safe harbor standards are met. The trust should include specific instructions regarding the management and supervision of the resources and to reduce the likelihood of abuse by others.

Once drafted, the trust must be funded (putting resources into the name of the trust) and administered (making distributions from the trust assets on behalf of the beneficiary). Distributions can be for a wide variety of things such as books, transportation to events, personal services, or movies the kinds of things anyone would need to lead a normal life within their personal circumstances. These are called distributions for supplemental services. Distributions cannot be for things that are provided by the major public assistance programs, such as food, clothing and shelter or in-kind services. These are distributions that would supplant the programs benefits. A trust committee can be assembled to get input from family and benefits experts to ensure the needs of the beneficiary are met while remaining compliant with the safe harbor rules.

The specific sums required to adequately provide supplemental services will be different for every family and will depend on their goals, the resources they begin with and the resources they can acquire for the trust. A financial planners experienced in special needs planning can help them identify their best financial opportunities to accomplish their objectives within their budget.

Special needs planning decisions straddle legal, financial and other advisor categories. It is important that the advisors be assembled to work as a team so each can bring their expertise to the decision-making process and to avoid planning blind spots. You should keep your advisors informed of the steps you are taking to eliminate blind spots that could erode the effectiveness of the plan.

Finally, the proper implementation of any estate plan requires a careful, consistent and structured maintenance and updating process to make sure the plan continues to meet the changing needs of the beneficiary while staying current with changing laws and financial needs. Failing to review and update your plan periodically could prevent you from taking advantage of opportunities to maximize your assets and protections.