

## Thinking Beyond Special Needs Trusts

By Frederick M. Misilo, Jr., Esq.

I have given some thought over the last several months to the long-term intended consequence of special needs planning. Certainly, special needs planning is more than a legal instrument; a special needs trust is supposed to direct the Trustee to do some things and refrain from doing others. It certainly is more than listing the names of individuals to serve certain functions in the future and act as fiduciaries. The long-term intended consequence of special needs planning is to create a set of structures, obligations, opportunities and choices designed to enhance the life of a family member with a disability so as to enrich life experience; empower self-determination; and build safeguards, supports and services that will last a lifetime.

The achievement of this lofty goal requires us to stretch our thinking beyond the traditional boxes most professionals work in when doing estate planning, financial planning and even person-centered planning. More than 25 years ago, I began working with a gentleman who convened a regular advisory group composed of friends, family and professionals to meet with him and his son with a disability. Over the last 25 years this group has seen many changes in their own lives and in the lives of my client and his son. The composition of the group has changed somewhat over time due to availability and to the natural occurrences of life. Yet this group is now poised to become the advisory committee for this gentleman's special needs trust for his son. This advisory committee will oversee, work with and replace, if necessary, the Trustee of the special needs trust.

**Major Take-away Point #1:** Special needs planning is a lifelong process, not a onetime event ceremony.

In their book "Members of Each Other: Building Community in Company with People with Developmental Disabilities," John O'Brien and Connie Lyle O'Brien identify five commitments that build a community for each of us. These five commitments are directly relevant in answering the question of how can we build in long-term positive consequences in our special needs planning. These commitments must be explored on a regular basis to make sure important persons remain involved and that all efforts are sustained in order to stay on target and move toward realization of goals and priorities. These five commitments are:

1. **Anchors:** These are the people who commit because they love the person and will be concerned about that person over time.
2. **Allies:** These are people who commit time and resources to make a jointly meaningful change through specific practical skills and abilities. These people can and will vary over time as situations and priorities change or become refocused.

3. **Assistants:** These are the people who help the person deal with the effects of the disability on a daily basis. A goal in providing assistance is to offer help without taking control.

4. **Associations:** These are the social structures that groups of people create to further their interests.

5. **Agendas:** These steps organize actions and work toward development and implementation of just and desired policies and results.

**Major Take away Point #2:** In relating these commitments to special needs planning, we must be both strategic (long-range) and tactical (short-term) in our thinking and planning about developing the desired conditions, supports and resources in a special needs plan. Just like race car drivers need to have short-range vision (i.e., what's right in front of them) as well as long-range vision (i.e., anticipating upcoming hills and curves in the roads as well as other cars!) in order to successfully and safely complete a race, we need to address the immediate tasks and issues of the special needs planning process as well as lay the groundwork for future decisions and actions.

A recurrent theme common in most dialogues about special needs planning is determining how much is enough. How much should I fund the trust? Should I start now? Answering these questions and plenty more is as difficult as guessing at what the economy, fiscal policy and a benefit structure will be in 20 or 30 years. An honest answer can only be an approximate estimate, based on what we know now, of what we can expect to realize in investments and financial products such as life insurance, long-term care planning considerations and a host of other issues. One saying I really like is "Trust in God, but tie up your camel." This saying speaks to the need to be practical, conservative and self-reliant in your approach to how much to set aside in a special needs trust. Parents, in my experience, grossly undervalue their own time, energies and abilities in advocating and monitoring services. While no one advocate or advisor can ever replace a parent, the essential advocacy and services monitoring can and must be replaced through other family members as well as through purchasing those services from qualified professionals. It is no secret that the adult services world requires vigilance on the part of all to ensure the highest degree of self-determination and quality of life. These conditions rarely just happen. They happen because there are active family members and advocates involved in the lives of the people receiving services.

---

**Major Take away Point #3:** If you are to err on the side of underfunding or overfunding a special needs trust, err on the side of overfunding it. The worst that will happen is that the interest remaining in the trust when the beneficiary dies is left to others in your family such as grandchildren or great-grandchildren.

Thinking about special needs planning as an ongoing process is critical if you hope to create a network of services and supports that will develop a “life of its own” over time. This planning should begin well before parents die or become unable to care for themselves. And it does take some thinking about how best to put a plan in place. In addition to the resources of the Fletcher Tilton Special Needs Practice Group, I have found the SUPPORTbrokers program (781-891-6270) to be an excellent source of support and guidance in developing plans that are both practical and visionary.

## RESPONSIVE SOLUTIONS

Two simple words that explain our commitment to you. Being responsive is a critical element in building a strong attorney-client relationship. Whether you are a new or existing client, we’ll be quick to respond to your needs with the knowledge necessary to find solutions to your legal concerns.



**Frederick M. Misilo, Jr.**

**P:** 508.459.8059

**F:** 508.459.8359

**E:** [fmisilo@fletchertilton.com](mailto:fmisilo@fletchertilton.com)

**Fletcher Tilton** <sup>PC</sup>  
Attorneys at law

[FletcherTilton.com](http://FletcherTilton.com)

*This material is intended to offer general information to clients, and potential clients, of the firm, which information is current to the best of our knowledge on the date indicated below. The information is general and should not be treated as specific legal advice applicable to a particular situation. Fletcher Tilton PC assumes no responsibility for any individual's reliance on the information disseminated unless, of course, that reliance is as a result of the firm's specific recommendation made to a client as part of our representation of the client. Please note that changes in the law occur and that information contained herein may need to be reverified from time to time to ensure it is still current. This information was last updated Summer, 2013.*