



SUMMER 2013

HELPING HAND

An Update from the Special Needs Practice Group

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EARLY INTERVENTION

- Special Needs Planning
- Medical Malpractice

SCHOOL AGE

- Special Education Advocacy
- Transition to Adult Services
- Special Needs Planning
- Guardianship and Alternatives

ADULT

- Special Needs Planning
- Adult Service Advocacy
- Special Needs Trust Admin.
- Guardianship and Alternatives

EXTENDED FAMILY

- Special Needs Planning
- Elder Law
- MassHealth Planning

PROBATE AND FAMILY COURT PRACTICE

- Estate Planning Petitions
- Adult Support Petitions
- Guardianship/Conservatorship

PRACTICE GROUP MESSAGE

By Frederick M. Misilo, Jr.



I will again be running in the New Balance Falmouth Road Race on August 11, 2013, to raise funds for Boston Children's Hospital as a member of its "Miles for Miracles Team." Having had two shoulder surgeries in the last five months, I've not had much opportunity to ready myself for this year's race. So, keep your fingers crossed, wish me luck and please contribute what you can on my webpage at the Boston Children's Hospital – Miles for Miracles website (howtohelp.childrenshospital.org/falmouth/page/Frederick-Misilo.htm).

This edition's lead article is a reflection on some of the more important, yet understated factors in

a special needs plan. Earlier this year, I had the opportunity to meet and present with the Indiana Arc's Pooled Special Needs Trust Executive Director at a conference in New York City. One of the benefits of meeting with colleagues from other parts of the United States is to gain new perspective on old concepts. The need to view special needs planning on a collaborative process beyond attorneys and financial planners was emphasized as a way to provide long term advocacy and services monitoring. **FT**

To contact me on these or any other related issues, my direct line is 508-459-8059 and my email address is fmisilo@fletchertilton.com.

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 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, to help 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 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

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THINKING BEYOND SPECIAL NEEDS TRUSTS

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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 Takeaway 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, 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 Takeaway 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. **FT**

SPECIAL EDUCATION: DISAGREEMENTS WITH THE SCHOOL DISTRICT

By Hillary J. Dunn, Esq.



Parents and school districts do not always agree about special education eligibility, assessments, services, and placement. As a starting point, it is almost always crucial for parents to have professional support for their position when they disagree with the school district's position. Parents have the right to obtain an independent evaluation if dissatisfied with the school district's evaluation and, in some circumstances, to have the school district pay for that independent evaluation. Parents always can have their child evaluated by whomever they wish at their own expense or through their health insurance.

When such disputes cannot be resolved between the parties at the Team level, parents have several dispute resolution options through the Bureau of Special Education Appeals ("BSEA"), including a facilitated IEP meeting, mediation, an advisory opinion, and a Due Process hearing. In Massachusetts, the BSEA is the administrative body authorized to address most issues arising under the IDEA, Section 504, and the state special education laws. Parents are often best served by consulting an attorney well before proceeding to the BSEA.

If you have concerns about your child's educational services, programming, or placement, contact Attorney Hillary J. Dunn at 508-532-3515 or hdunn@fletcherilton.com. We represent students with disabilities and their families through all stages of advocacy in the special education process including assessment, IEP development, implementation and placement. We assist our clients at school meetings, in mediation and in hearings before the Bureau of Special Education Appeals. **FT**

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Send an email to bsutphen@fletcherilton.com with the subject "SNP Newsletter" and we'll add you to our list!

UPCOMING SEMINARS

TRISOMY 18 ANNUAL CONFERENCE

July 19, 2013

Speaker: Theresa M. Varnet, Esq.

Location: Savannah, GA

LIFELONG PLANNING FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

September 14, 2013

Speaker: Theresa M. Varnet, Esq.

Location: The Arc of LA, Gonzalez, LA

SHARED LIVING CONFERENCE

September 26, 2013

Speaker: Frederick M. Misilo, Jr., Esq.

Location: College of the Holy Cross
Hogan Center, Worcester, MA

SPECIAL NEEDS BRIEFING FOR MA CERTIFIED FINANCIAL PLANNERS

September 30, 2013

Speakers: Frederick M. Misilo, Jr., Esq.
& Theresa M. Varnet, Esq.

Location: Sheraton Hotel, Framingham

AUTISM SPEAKS GREATER BOSTON WALK NOW FOR AUTISM

October 6, 2013

Speaker: Fletcher Tilton Special Needs Practice Group

Location: Suffolk Downs, East Boston, MA

ANNUAL SPECIAL NEEDS TRUST SEMINAR

November 2, 2013

Speaker: Fletcher Tilton Special Needs Practice Group

Location: DoubleTree Hotel, Westborough, MA

To arrange a seminar by a representative of the Special Needs Practice Group, contact Fred Misilo at 508-459-8059 or fmisilo@fletchertilton.com.

SPECIAL NEEDS TRUSTS FOR DISABLED CHILDREN OF MILITARY RETIREES



by Theresa M. Varnet, Esq.

If you are a military retiree and a parent of a special needs child, a bill in Congress will make it easier for you to provide for your special needs child after you die. The military allows retirees with special needs children to participate in the Survivor Benefit

Plan, which permits monthly benefit stipends up to 55% of the military retiree's pension to be paid for the benefit of a disabled child. Currently this survivor benefit must be paid directly to the disabled child. The Disabled Military Child Protection Act will allow the survivor benefit to be paid directly to a d4A or d4C special needs trust. If the benefits are distributed directly to the trust, the child will remain eligible for needs-based benefits such as Supplemental Security Income ("SSI") or Medicaid.

On May 23, 2013, Senator Kay Hagan (D-NC) introduced S.1076, which will provide for the payment of monthly survivor annuities under the Survivor Benefit Plan to be paid to a special needs trust for the benefit of a veteran's disabled dependent child. It is anticipated that Congressman Jim Moran (D-VA) will introduce a similar bill on June 3rd when the House returns from recess. A press conference with Senator Hagan and Congressman Moran will be held on June 4th to promote the bill.

Currently, veterans are allowed to designate a certain percentage (up to 55%) of their Survivor Benefit Plan to go to a dependent disabled child upon the veteran parent's death. Because of the size of the pension benefits, in some cases, this places the disabled child in a position that s/he has a significant spend-down requirement each month in order to receive Medicaid. This bill, if passed, will ensure that a dependent disabled child will continue to qualify for Medicaid without a spend-down. The disabled adult child will also qualify for or remain eligible for other needs-based benefits such as food stamps or Section VIII housing subsidy after the veteran parent dies. It is important that you contact your legislators to ask them to support and vote for this critically needed legislation.

Note: There is a major distinction between a d4A or a d4C special needs trust and the typical trust that a parent provides in a will or living trust for a disabled child. The d4A or d4C special needs trust is funded with money that belongs to the disabled individual (called a first-party special needs trust). The type of trust that parents create in their wills is funded with an inheritance that never belonged to the disabled child and is considered a "third-party-funded special needs trust." All first-party special needs trusts must contain a payback clause indicating that state and federal funds under Medicaid that are paid for the benefit of a disabled beneficiary be paid back from the trust should there be funds remaining upon the death of the beneficiary. If the first-party trust has been spent down for the sole benefit of the beneficiary, no payback is required. The state will require a detailed accounting to confirm that all funds were spent down for the beneficiary and that funds were not used for the benefit of others. **FT**



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Upcoming Seminars Register Now!

The Fletcher Tilton Special Needs Practice Group provides legal counseling, advocacy and innovative solutions on behalf of individuals with differing abilities and their families. We strive to serve as a reliable, trusted advisor committed to providing excellent service to our clients throughout their lifetime. We recognize the importance of treating our clients with respect and dignity.

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