



# HELPING HAND

A Monthly Update from the  
Special Needs Planning Practice Group

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September October 2009



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### Special Needs Planning 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 & Alternatives

### Adult

Special Needs Planning  
Adult Service Advocacy  
Special Needs Trust Admin.  
Guardianship & Alternatives

### Extended Family

Special Needs Planning  
Elder Law  
MassHealth Planning

### Probate and Family Court Practice

Estate Planning Petitions  
Adult Support Petitions  
Guardianship

## The Special Needs Planning Practice Group

*A Commitment that Lasts a Lifetime*

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September - October 2009

## A MESSAGE FROM THE PRACTICE GROUP CHAIR

By Frederick M. Misilo, Jr., Esq.



The featured article for this edition deals with the familiar and important issue of how grandparents can help with the special needs planning for their grandson or grand-daughter. I am gratified that Attorney Theresa Varnet took the time to share her insights and guidance in this important area by authoring this article. Attorney Varnet stresses the importance of integrating the estate plans of grandparents with the special needs planning documents of their adult son or daughter. This is an incredibly important planning pointer for families. I hope you find this article a useful tool to, perhaps, begin discussions within your family about how to coordinate special needs planning on behalf of your family member with a disability. If you are interested in learning more about this topic, the FTW Special Needs Practice Group will be hosting a seminar for grand-parents on this topic on the evening of November 17th at the Courtyard Marriott Hotel in Marlboro, MA. Please contact Sara at (508) 459-8021 or [smurphy@ftwlaw.com](mailto:smurphy@ftwlaw.com) to register.

This past summer saw the loss of two vital and incredibly important leaders in the disability community – Eunice Kennedy Shriver and Senator Edward M. Kennedy. By creating Special Olympics, Mrs. Shriver gave individuals with disabilities the opportunity to grow, learn and compete on the athletic field. Millions of athletes compete in Special Olympics every year in hundreds of nations world-wide. Through their

participation, athletes gain self-confidence, experience the thrill of competition and are encouraged to develop their abilities to their full potential. The encouragement and passion of Mrs. Shriver gave to Special Olympics and to its athletes can best be described in her own words delivered in 1987 at the Special Olympics World Games in South Bend, Indiana:

“The right to play on any playing field.  
You have earned it.  
The right to study in any school.  
You have earned it.  
The right to hold a job.  
You have earned it.  
The right to be anyone’s neighbor.  
You have earned it.”

If you are interested in learning more about Eunice Kennedy Shriver’s life and work, I encourage you to visit [www.eunicekennedyshriver.org](http://www.eunicekennedyshriver.org).

As I am sure you are aware, Senator Kennedy’s legislative achievements on behalf of individuals with disabilities are unparalleled in American history. Consider the following mere sampling of his legislative accomplishments. Senator Kennedy sponsored the Children’s Health Insurance Program (CHIP) which currently provides 7,000,000 children with health care, the Americans with Disabilities Act of 1990, the Protection and Advocacy for Mentally Ill Individuals Act of 1986, the Civil Rights Commission Act Amendments of 1978, the Civil Rights for Institutionalized Persons Act of 1980, Fair Housing Act Amendments of 1988, the

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# What Grandparents Can Do To Help Their Adult Child Who Has A Child With Special Needs

By Theresa M. Varnet, M.S.W., J.D.

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When I was asked to write this article, it brought back wonderful memories of the help that my mom and dad gave me, my husband and my daughter over the first 24 years of our daughter's life. My parents passed away prior to Jen's 25th birthday. The help they provided, especially in the first 10 years of Jen's life, was invaluable. I don't know how my husband and I could have raised Jennifer as well as we did without the help and guidance of my parents.

Jennifer, who is now 41 years old, was born with Tuberous Sclerosis (TS). TS is a genetic condition that results in seizures, heart and kidney complications, and in some cases developmental delay. Jennifer, unfortunately, had all the adverse health conditions associated with TS as well as a moderate to severe developmental delay. When Jen was around 4 years old, she was also diagnosed as having Autism. My husband and I, as young parents, were, on occasion, overwhelmed by Jen's health and educational needs.

My parents, from the very start, were always there for us. They were not wealthy so they were limited in helping us financially but they were always there for us in other ways. They were always there to lend a sympathetic ear, laugh with us, cry with us, offer us relief from the day to day responsibilities of raising a child with special needs and advocating for Jen when needed. Their time, love and attention that they showered on Jennifer were precious gifts.

I credit my parents' help with the fact that my husband and I survived this challenge as a couple and with our becoming the kind of parents Jen needed in her life. As a former social worker and currently in my position as an attorney, I see similar situations among my clients where having supportive grandparents has made all the difference in making

one's life experiences in raising a special child a positive one. Having the love, acceptance and support of one's parents, makes it easier to raise a child with special needs.

I've gleaned the following DO's and DON'Ts list based on my own experience and that of my clients.

#### DO:

- Accept your grandchild for who they are.
- Be understanding of your grandchild's behavior.
- Support your child's parenting decisions.
- Become as knowledgeable as you can about your grandchild's condition.
- If distance permits, spend time with your grandchild.
- Provide respite for your adult child by offering to sit for your grandchild when possible.
- Offer to take your grandchild to appointments or offer to accompany your child and grandchild to doctor's visits, school meetings, etc.
- For long distance grandparents, stay in touch via telephone calls, letters, send cards of encouragement and humor and/or send gift cards for housekeeping help, massage, dinner out or other luxury that your adult child may not be able to afford.
- Offer financial assistance when able to do so. Grandparents can pay for any amount of medical or education services when paid directly to the provider for services without incurring gift tax consequences.
- Get financial advice from a financial planner who is familiar with special needs financial planning and plan early for your grandchild's future.
- Change your wills or living trust documents so that any share of your inheritance that may be distributed to your grandchild with special

needs will be distributed to a properly written SPECIAL NEEDS TRUST.

- Consider a "2nd to Die/Survivorship" life insurance policy to fund a special needs trust to maximize resources in a special needs trust. This type of policy is little known but is ideal for funding a special needs trust.
- Support Federal Legislation to establish tax exempt accounts for individuals with a disability. On Feb. 26, 2009 legislation was introduced called Achieving a Better Life Experience Act of 2009 (ABLE Act of 2009). This legislation will allow individual tax payers a tax deduction of up to \$2,000 per year for contributions to an ABLE account. The ABLE account will be disregarded in determining eligibility for Medicaid benefits and other means tested programs such as SSI, Section 8 and food stamps. The funds in these trusts can be used for education, housing, transportation, employment support, medical care and certain life necessities that are related to the individual's disability.

#### DON'T:

- Don't deny your grandchild's condition - denying it exists doesn't make it less real.
- Don't judge your child's parenting skills. Parents who have children with hyperactive or behavior disorders need your support to help them cope with the stresses their child's behavior creates. It is demoralizing to be judged by those closest to them.
- Don't place blame for your grandchild's condition on your child. If your child abused drugs or alcohol while pregnant, intervention may be needed if there is another pregnancy. In most cases blaming

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## We're Expanding! New Hyannis Office



FTW now has an office located at 171 Main Street in Hyannis, MA for added convenience for our clients in Southeastern MA, Cape Cod and the Islands.

Parking is conveniently located at the back of the building.

## Thank You!

With Your help, Fred raised over \$2,500!

On Sunday, August 9, Attorney Fred Misilo ran the 37th CIGNA Falmouth Road Race. Thanks to everyone who supported Fred, and in turn, are supporting Children's Hospital, Boston.

## GRANDPARENTS *continued from page 2*

- your adult child often escalates feelings of guilt.
- Don't place blame for your grandchild's condition on his or her teacher or other helping professionals. Blaming the messenger for informing parents of their child's special needs is counter productive.
  - Don't purchase U.S. Savings Bonds or fund a Uniform Transfers to Minor's Account in your grandchild's name. These assets may jeopardize your grandchild's eligibility for needs based government benefits for which s/he may qualify as a result of his or her disability. Even if your grandchild doesn't qualify for needs based benefits, if his or her disability is a behavior or conduct disorder disability, s/he will have access to these funds when s/he turns 18 or 21. If your grandchild lacks maturity or is behaviorally challenged, these assets could be at risk. ●

*The FTW Special Needs Planning 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 lifetimes. We recognize the importance of treating our clients with respect and dignity.*

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## CONGRATULATIONS! Attorneys David Guarino and Elise Kopley

We are pleased to announce that 2 FTW attorneys, David Guarino and Elise Kopley, have been chosen to present seminars for MA Continuing Legal Education (MCLE) and for Suffolk University Law School respectively. Mr. Guarino will present "Estate Planning for the Moderate Estate" on 4 dates in October and Ms. Kopley will be on a panel presenting "What Guardianship and Conservatorship Practitioners Need to Know About the New Law" on November 6.

## MESSAGE

*continued from page 1*

American with Disabilities Act of 1990, and the original 1975 Education for All Handicapped Children's Act together with the Individuals with Disabilities Act (IDEA) of 1990, the 1997 amendments to IDEA and the reauthorization of IDEA in 2004. If a member of your family receives or has received early intervention services, special education services, government sponsored health care, Medicaid waiver services, a housing subsidy, vocational training or has found vindication by successfully asserting a disability discrimination claim, you have Senator Kennedy to thank.

Finally, I am pleased to announce that Fletcher, Tilton & Whipple has opened an office in Hyannis at 171 Main Street to better accommodate our clients in southeastern Massachusetts, Cape Cod and the Islands.

If you would like to communicate with me on any special needs planning issue, please feel free to contact me at (508) 459-8059 or fmisilo@ftwlaw.com. ●

## Upcoming Seminars

For a Complete List & Details, visit [ftwlaw.com](http://ftwlaw.com)

### October 18

*Walk Now for Autism - Meet Us There!*  
**At:** Suffolk Downs, E. Boston

### October 24

*Annual Special Needs Trust Training*  
**Speaking:** Fred Misilo, Esq.  
**At:** Courtyard Marriott, Marlboro

### November 7

*Williams Syndrome Conference*  
**Speaking:** Theresa Varnet, Esq.  
**At:** Marriott, Newton

### November 10

*BIA-MA Pediatric Brain Injury Conference*  
**Speaking:** Fred Misilo, Esq.  
**At:** Best Western Royal Plaza, Marlboro

### November 11 & 12

*Arc US Conference & Pre-Conference*  
**Speaking:** Theresa Varnet, Esq.  
**In:** Pittsburgh, PA

### November 17

*Grandparents & Special Needs Planning*  
**Speaking:** Fred Misilo, Esq. and Jason Bourque & Kim Conroy of New York Life  
**At:** Courtyard Marriott, Marlboro  
**Sponsored by:** FTW & New York Life