Planning should include the whole family’s needs as well as those of the adult child with special needs. Here’s how to put the pieces together.

As a parent of a 46 year old daughter challenged with intellectual disabilities, I used to lie awake at night worrying about who is going to look after Jennifer when my husband and I die. Parents often worry about unknowns such as where their adult child with life long disabilities will live; who will advocate for their child, what kind of vocational, recreation, residential and support services will their child need and receive, etc. Parents will gain great peace of mind if they take the time to plan for their child’s future while they still have the health, time and energy to do so. Planning is more than just having a will and perhaps a special needs trust in place. It is working with the agencies within the community the family anticipates the adult child will be living when the parent(s) die to ensure that proper supports are in place. This type of planning often requires the involvement of significant others which include siblings, other family members, family friends and professionals such a financial planner, attorney, social worker, etc.

Within the so called typical population, few parents plan for their own aging. An AARP survey indicates that nearly 70% of aging parents fail to discuss issues related to aging with their adult children. It is therefore no surprise that so few families supporting adults with life long disabilities have had meaningful discussions concerning viable long term plans for their son or daughter who will need life time supports. Aging parents owe it to themselves, to their typical adult children and especially to the adult child challenged with life long disabilities to begin the process of making plans which addresses the long term care needs for themselves as they age as well as for the family member in need of long term supports.

While opening a dialogue with other family members about long term care plans is important, it is impossible to resolve this issue in a single talk. Planning for one’s old age and the future of a family member is an ongoing process. The one thing we all know is that life is filled with the unexpected. The plan made must be reviewed every few years to be sure the plan still reflects everyone’s needs, not just the needs of the adult child with a disability. The needs and circumstances of siblings and other family members who may be called upon to play a role as advocate, caregiver, guardian, trustee or in some other meaningful support role must be reviewed as their life situations may have changed since “the plan” was first put into place.

My advice to families when developing a life care plan for the family member needing life long care is to “hope for the best but prepare for the worst.” Parents will often say, I’m not worried because I know my daughter will take her brother in and care for him. They may assume this without ever discussing it with their typical child. Perhaps they have shared their expectations with their typical child but the typical child does not express his/her concern about making a lifetime commitment for fear of angering or upsetting the parent(s). Relying on adult siblings to fill in as caregivers is often not realistic nor is it often in the best interest of the adult who may desire independence from his or her family but may need help in gaining independence. It is important for adult children to be honest with their parents about what they are prepared to do for their sibling. Even for those families whose adult child prefers to live with a sibling, and the typical sibling is willing to assume responsibility for life time care, parents need to plan for an alternate living arrangement.

Situations change and, as a result, a life care plan may need to be adjusted. In one family, it was decided that the daughter challenged with intellectual disability was to live with her younger sibling. The sibling and her husband and 3 children were all in agreement that the best place for ‘Julie’ was to live with them when the parents died or were not able to provide for ‘Julie.’ Unfortunately, the younger sibling was diagnosed with breast cancer in her early 40’s. Following her diagnosis and treatment, she felt her own future was uncertain and she was no longer able to commit to caring for her sister’s life long needs. Julie has since moved into a supported living program with 2 women challenged with similar disabilities. She is still very close to her sister and visits often but her sister no
longer has to worry about what will happen to Julie if her cancer returns. Julie’s parents changed their estate plan to provide Julie’s share of the inheritance be distributed to a special needs trust which will provide funds for supplemental needs and a higher quality care for Julie in her state funded program.

In another family, two of the siblings agreed to share in the responsibility of caring for their adult brother who was challenged with Down Syndrome. ‘Brian’ was a beloved member of the family with a wonderful sense of humor and ability to self care for all of his personal needs. Shortly after Brian’s parents died, he developed Alzheimer disease at the early age of 50 and regressed very quickly to the point that he needed help with bathing, toileting and other personal hygiene needs. It soon became difficult for the two siblings to care for him and he was eventually placed in a nursing home. Fortunately Brian’s parents had provided for him with a special needs trust which meant his inheritance did not have to be spent down on nursing home care. These two cases illustrate the need to always plan for the worst in case the unexpected occurs.

In talking with my clients about aging, theirs and their child’s, I recommend that they begin a discussion with their children. Where possible, the discussion should include the child with life long planning needs. Self advocates have a saying “nothing about me without me.” How can parents plan for their child’s future without gaining input from their child as to what his preferences as to where and with whom he lives, etc.? Parents need to ask their children and other family members for their advice and wishes regarding future roles and responsibilities. A plan made in the absence of input from all of the key players is doomed to failure.

Parents need to meet with an attorney well versed in special needs planning to draft the legal documents one will need in the future. (Finding an attorney well versed in special needs planning is difficult. Families may want to contact The National Academy of Elder Law Attorneys (NAELA.org) or The Academy of Special Needs Planners (ASNP.org) for a list of attorneys who concentrate in special needs law in their area. An attorney who is a member of one or both of these two professional organizations will be familiar with special needs planning. Parents may also want to meet with a financial planner who can advise them on how to best fund the special needs trust. A financial planner can also assist parents in changing the beneficiary designations on non probate assets such as IRAs, retirement funds, life insurance policies, etc. so that the share for the family member with life long disabilities is directed to a special needs trust.

Legal documents should, at a minimum, include the following:

1. Pour over will which will provides for the share of the family member with long term needs to pour over into a properly worded special needs trust;
2. Properly worded special needs or supplemental needs trust;
3. Powers of attorney for health care and property for the parents and grandparents. The power of attorney for property should include Medicaid gifting powers so that if the elderly parent or grandparent enters a nursing home, the parent’s or grandparent’s assets can be preserved for the benefit of a child or grandchild who is disabled as defined by the Social Security Act. (Note: There is no 5 year look back period for transfers to a qualified trust for a special needs child. This enables the elderly parent or grandparent to qualify for Medicaid to pay for his/her long term nursing home and preserves the net worth of the parent or grandparent for the benefit of the adult child challenged with disabilities.);
4. Guardianship documents if needed. If the family member does not need a guardian, it is recommended that he or she should sign durable powers of attorney for health care and property designating a family member or friend as agent. This is important for all persons over the age of 18 but especially critical for persons with life long care needs who often need an advocate to assist them with navigating the health and human services care systems. Our firm has created a customized form that we call a Power of Attorney for Advocacy which designates an agent to review records, release records, attend meetings, apply for benefits, etc. This form enables a trusted friend or family member to formally advocate on behalf of the family member who is challenged with a disability. The POA for Advocacy overcomes the confidentiality shield that often prevents friends and relatives from being effective advocates due to the restrictions of the Health Insurance Portability and Accountability Act.

In addition to the above documents, it is helpful for a parent of a child who is non verbal or unable to communicate his wishes due to his disabilities, to write a letter of direction. The letter of direction is an informal document that provides future caregivers and significant others with important information that provides continuity for the subject of the letter of direction. A letter of direction should be reviewed no less than once per year to be sure it adequately reflects the current needs and wishes. A typical letter of direction will include important information such as:

- the names, addresses and phone numbers and relationships of all significant family members
- a list of significant others such as respite care workers, social worker, job coach, neighbors who may be of assistance as well as how to contact these individuals
- the location of important documents such as wills, trust, birth certificates, guardianship order or POAs, insurance policies, deeds and titles to properties as well as burial plans if any

Updated information about your and your family member’s medical history including a list of names, addresses, phone numbers, hospital ID numbers for all the doctors and other therapists who treat the individual may also be helpful.
A letter of direction also enables parents to memorialize their hopes, dreams and wishes for their family member. This last section often provides guidance for the persons who assume the care giving role or who are trustees of a special needs trust. MetLife Center for Special Needs Planning provides an excellent sample letter of direction form which can be accessed on the MetLife website.

It is also wise to leave written information regarding your financial assets, social security numbers and other confidential matters in a place of safe keeping so that assets are not lost when you die. Often times, pension benefits, insurance policies, and other assets are not claimed because the parent did not inform their future executor or successor trustee of the existence of these assets.

By making sure their financial documents are in order, that their adult child or family member is receiving all the benefits he or she is entitled to, applying to the relevant social service agencies for life time supports, working with agencies and family members to develop a plan for future care and supports and by memorializing the family’s wishes in a current letter of direction will enable parents and persons with long term disabilities to sleep better at night. A parent who has completed the above steps, has the peace of mind of knowing they have done what they could for their son or daughter challenged with a life long disability.

Jennifer, by the way, moved into a shared living arrangement with a woman who is a Teacher’s aid in the public school. This woman enables Jen to live independently and for Jen, this is a terrific arrangement. My husband and I purchased a home in our neighborhood where Jen and her housemate live. Jen receives a Section 8 voucher for rent and funding under a Title XIX Medicaid waiver program which provides the supports and services Jen needs to live independent of her parents. Oh, and yes, I do sleep a lot better these days.

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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.

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RESOURCES
The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
800-433-5255 | www.thearc.org

National Academy of Elder Law Attorneys – NAELA
1577 Spring Hill Road, Suite 220
Vienna, VA 22182
703-942-5711 | www.naela.org

Academy of Special Needs Planners – ASNP
260 West Exchange Street, Suite 004
Providence, RI 02903
866-296-5509 | www.specialneedsplanners.com

Special Needs Alliance
6341 E. Brian Kent Drive
Tucson, AZ 85710
(520) 546-1005 | Toll-Free (877) 572-8472
www.specialneedsalliance.org

MetLife Center for Special Needs Planning
300 Davidson Avenue
Somerset, New Jersey 08873
877-638-3375 | www.metlife.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 June 2014.
A special needs trust is a way to provide that an inheritance intended for the benefit of a family member with a disability is left in a manner to supplement government benefits rather than supplant them. When a person is challenged with a disability, s/he may qualify for several needs based government benefits such as SSI, Medicaid, SNAP, Subsidized housing, fuel assistance, etc. If a brother or sister is left a direct inheritance, this may result in a loss of benefits that are critical for his or her support and independence. If the family member with a disability is left an inheritance in a special needs trust, s/he gets the best of both worlds: continued eligibility for needs based benefits and a private source of funds to enable him or her to live a higher quality of lifestyle than s/he could otherwise afford.

Drafting a Special Needs Trust is the first step in placing a safety net under a child or other family member with special needs to ensure a quality life for him or her. While parents often rely on siblings or a cousin or close family friend, to monitor how funds are spent and that the special needs family member reaps the greatest benefit from having a special needs trust, the knowledge of how to manage a special needs trust is not intuitive. Families often name siblings in a number of fiduciary positions such as guardian, trustee of a special needs trust, executor of their estate, trust protector, etc. It is important for families to have a talk about how they have provided for the family member with special needs with the adult child or other persons they have designated as trustee, guardian, trust protector so that this person is aware of what is expected of him or her. Knowledge is power and if the sibling knows what is expected of him or her, s/he is in a better position to educate him/herself about what they need to know and learn for their future role as trustee or trust protector of a special needs trust.

If you are the sibling of a brother or sister challenged with a disability and your parents haven’t said anything to you about their life-long plans for your brother or sister, you may want to initiate the conversation with them. You will want to know what their hopes and dreams are for your sibling and what your role is, if any, in implementing that life-long plan. If there isn’t a plan, this may be the perfect opportunity to work with your parents to form a plan this is realistic and possible given the long waiting lists for services in most states.

Parents should let their adult children know if they have included a special needs trust in their wills or living trusts that provides for the sibling with a disability. Some parents have merely disinherited the child with a disability and left what is commonly referred to as a morally obligated gift to the other sibling or all siblings with a request that they use the extra inheritance for the benefit of the brother or sister with a disability. This may create a number of legal problems for the relied upon sibling. If the special needs child has been disinherited, the parents have created a potential conflict of interest between the typical siblings and the special needs sibling. A probate court may appoint an independent guardian to look into contesting the will because the person named as guardian is also named to receive a larger share of the estate. The naming of a GAL may result in substantial cost to the estate as well as delay distribution for many months or longer.

While no parent enjoys discussing what is going to happen to their special needs child when they die, this is a discussion that can make a huge difference in the success of their plans for their special needs child. Fletcher Tilton, P.C. offers an annual seminar on How to Manage a Special Needs Trust. It is highly recommended that if a parent has named an individual to serve as trustee, that this future trustee be encouraged to attend the annual training in person or via webinar. Attending this training may open the door to a discussion of how the parent wants the funds s/he has left for the special needs child to be used and be sure that everyone is on the same page.

The next seminar on How To Manage a Special Needs Trust is scheduled for Saturday, November 8, 2014 from 8:00 - 1 P.M. This training can be used as an opportunity to educate your typical child (children) of their role in assisting their brother or sister live as quality a life possible as well open the door to communication about a topic
which is difficult for all of us. If distance or your schedule prevents you from attending in person, you may want to attend via webinar. Information about registering for this annual training is available on the website of FletcherTilton.com

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Government Benefits and Updates on Emerging Issues

Theresa Varnet, Esq.
Negotiating the Government Benefits Maze

Types of Benefits

- Entitlement Benefits
- Needs Based Benefits
- Sliding Scale Fee Benefits
Eligibility Criteria

Supplemental Security Income (SSI)
Social Security Disability Income (SSDI)

**SSI**
- Needs based
- MA Health
- May 2012 changes in POMS concerning self-settled special needs trusts

**SSDI**
- Entitlement based on contributions paid to Social Security Administration

**CDB Benefits**
- Benefits to a person with a continuous disability, onset prior to age 22, with a parent covered by Social Security who has died, retired, or become disabled
- Medicare

**Sliding Scale Fee Benefits:** Food Stamps, Section 8, Commonwealth, Commonwealth Choice, PCA, Adult Foster Care, Affordable Care Act new Medicaid expansion
Importance of Special Needs Trusts

• Cutback in state and Federal spending over past 5 years;
• Anticipated future reduction in federal and state expenditures will result in greater loss of services;
• Potential Medicaid waiting lists; and
• Threat of Federal Block Grant for the States
Importance of Special Needs Trusts

Special Needs Trust
- Private funds

Government Resources
- Future reductions anticipated
- Growing Federal deficit
- State spending reduced
- Medicaid Block Grants
- Medicaid waiting list

Private funds
Potential Beneficiaries of a Special Needs Plan

• Anyone receiving a Medicaid benefit such as group living setting, day habilitation, etc.
• Anyone who is receiving or has received special education services;
• Someone with a chronic medical disability;
• A recipient of Supplemental Security Income, Social Security Disability Income, Disabled Adult Child Benefits;
• A family member who is or may be going through a divorce;
• A family member who is “always behind in their bills”.
Recent Developments

- Affordable Care Act implementation schedule and implications in special needs planning
- Achieving a Better Life Experience ("ABLE Act")
- Sole Benefit Rule Changes in the POMS
- Fiduciary liability case development
Making DISTRIBUTIONS to Maximize Benefits

- Determine benefits received annually or more often
- No cash directly to beneficiary
- All distributions to 3rd parties or vendor
- Distributions to a guardian as agent of Trust not in role of guardian
Basic Management Tips

• Read Trust – *then read it again*
• Contact beneficiary or representative to determine priorities
• Determine a budget or spending plan
• Avoid commingling assets belonging to beneficiary with a 3rd party special needs trust
• Use a taxpayer ID number
• Maintain accurate records
• File all state & federal tax returns when due
• File annual accountings with the beneficiary or his/her legal representative
BIography

Theresa M. Varnet
Of Counsel
P: 508.459.8091 | E: tvarnet@fletchertilton.com

Practice Focus
Theresa M. Varnet is Of Counsel with the firm, and her practice concentrates on Special Needs Planning. Her clients include families and individuals with special needs of all types.

Biography
Of Counsel with the firm, Theresa M. Varnet has been an advocate for persons with disabilities for over 40 years. In addition to being a lawyer, she is a certified teacher, licensed social worker and the parent of a disabled adult daughter. She has served as Social Services Director in a residential school for children with multiple disabilities, Coordinator for a Special Education Cooperative, and as a Citizen Advocacy/Disability Rights Coordinator. While living in the Sultanate of Oman, she assisted the Omani Ministry of Social Affairs in developing the first preschool program for children with handicapping conditions.

Her experience includes extensive work in the area of in-service training with families, special educators, social workers and other professionals. A frequent speaker for volunteer and professional groups, Attorney Varnet presents numerous seminars on special needs planning and advocacy across the U.S. She has also been interviewed on NPR’s “All Things Considered” radio program.

An active volunteer in the national, state and local chapters of The Arc, Attorney Varnet is immediate past Chair of the Special Needs Law section of National Academy of Elder Law Attorneys (NAELA), and is a member of TASH, Alliance for Mentally Ill (AMI), The Autism Society, past member of the Developmental Disabilities Council in Massachusetts and Kentucky, and past member of the Governor’s Advisory Panel on Special Education in Kentucky.

Admitted to practice in the Commonwealth of Massachusetts and the State of Illinois, Attorney Varnet received her B.A. from the University of Massachusetts and her Master’s in Social Work from the University of Connecticut in 1979. She earned her J.D. from DePaul University in 1989. She divides her time between her Chicago-based practice at Spain, Spain & Varnet and the Massachusetts offices of Fletcher Tilton PC.

Attorney Varnet’s administrative assistant is Wilma Vallejos, (508) 459-8079.

Admitted to Practice
The Commonwealth of Massachusetts
The State of Illinois

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EDUCATION & CERTIFICATIONS
Law Degree; DePaul University
Master’s Degree in Social Work; University of Connecticut
Undergraduate Degree; University of Massachusetts
Certified Teacher
Licensed Social Worker

MEMBERSHIPS
Immediate past chair of the Special Needs Law Section of National Academy of Elder Law Attorneys (NAELA)
National, state and local chapters of The Arc
American and Worcester County Bar Associations
Academy of Special Needs Planners (ASNP)
TASH
Alliance for Mentally Ill
The Autism Society

RECOGNITION
Member, Developmental Disabilities Council, Massachusetts and Kentucky
Nominated to the Governor’s Advisory Panel on Special Education in Kentucky

SIGNIFICANT REPRESENTATION & ACHIEVEMENTS
A frequent speaker, Attorney Varnet has presented at the national conferences of TASH, American Association for Intellectual Disabilities (AAID), and The Arc, among others. With Richard Spain, she is the coauthor of the booklets “Home Control through Estate and Financial Planning,” “Estate Planning for the Aging Incapacitated Client in Massachusetts,” and “Special Needs Trust.” Quoted on numerous occasions in national journals and publications, she has appeared in the Kiplinger Retirement Report, The New York Times, The Chicago Tribune, the AARP Bulletin, Exceptional Parent magazine and National Public Radio’s “All Things Considered.”

ARTICLES
• Using Qualified Special Needs Trusts to Protect Assets When a Parent or Grandparent Enters a Nursing Home
• Achieving a Better Life Experience Act of 2009 (ABLE Act)
• What Grandparents Can Do to Help Their Adult Child Who Has a Child with Special Needs
• Futures Planning for Families Supporting Adults with Life-Long Disabilities
• Home Control Through Trust and Estate Planning (booklet)
• Preparing a Life-Planning Document for Your Disabled Family Member
• Revised Regulations for SSI Eligibility
• Advice and Guidance for the Financial Planner Advising Parents of Children with Life- Long Disabilities
• Special Needs Trust Management - A Legal Resource Guide