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**FUTURE PLANNING FOR FAMILIES SUPPORTING ADULTS WITH LIFE LONG  
DISABILITIES**

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

As a parent of a 42 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 (specialneedsplanners.com) 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 IRA's, 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 provides for the share of the child 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. The power of attorney for property should include Medicaid gifting powers so that if the elderly parent enters a nursing home, the parent's assets can be preserved for the benefit of a child 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 to qualify for Medicaid to pay for his/her long term nursing home and preserves the net worth of the parent for the benefit of the adult child challenged with disabilities.);
- 4) Guardianship documents if needed. If the adult child 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. I have created a customized form that I 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 POA's, insurance policies, deeds and titles to properties as well as burial plans if any.

Updated information about your and your child's medical history including a list of names, addresses, phone numbers, hospital ID numbers for all the doctors and other therapists who treat your child may also be helpful.

A letter of direction also enables parents to memorialize their hopes, dreams and wishes for their child. This last section often provides guidance for the persons who assume the care giving role or who are trustees of a special needs trust. MetDESK provides an excellent sample letter of direction form which can be accessed on the MetDesk 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 is receiving all the benefits he or she is entitled, 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.

## RESOURCES

The Arc of the United States	1010 Wayne Avenue Suite 650 Silver Spring, MD 20910 (800)433-5255	<a href="http://www.thearc.org">www.thearc.org</a>
MetDesk MetLife Mature Market Institute <sup>1</sup>	(800) 638-5433	<a href="http://www.metlife.com">www.metlife.com</a> <a href="http://www.maturemarketinstitute.com">www.maturemarketinstitute.com</a>
National Academy of Elder Law Attorneys – NAELA	1577 Spring Hill Road Suite 220 Vienna, VA 22182 (703) 942-5711	<a href="http://www.naela.org">www.naela.org</a>
Academy of Special Needs Planners – ASNP	260 West Exchange St. Suite 004 Providence, RI 02903 (866) 296-5509	<a href="http://www.specialneedsplanners.com">www.specialneedsplanners.com</a>

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<sup>1</sup>The MetLife Mature Market Institute is the company's information and policy center on issues relating to aging, retirement, long term care, and the mature market.