Futures Planning for Families Supporting Adults with Life-long Disabilities

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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 (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.

In addition to the documents listed at the left, 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.

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

1) Pour over will which will 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.

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If you would like to learn more about Fletcher Tilton’s Elder Law & Special Needs Attorneys, contact: Frederick Misilo, Jr., Practice Group Leader
Estate planning for parents with a dependent who has a disability is a complex process. Most parents find it difficult to even contemplate their death and, as a result, planning can be an upsetting experience for families. It is not unusual for parents to feel either too young to consider estate planning or to feel they have so few assets that this type of planning is not applicable to them. You need not be wealthy or old to begin seriously considering the need to write a will and a supplemental or “special needs” trust if you have a family member who needs government benefits to ensure that he or she receives the care and support necessary over a lifetime. But in order to do this, you must plan carefully.

For most families, planning means having a legal will drafted to ensure that your assets go to people you designate and to name a guardian for a minor or adult child with a disability who needs guardianship. If you die without a will, the state determines how your assets are distributed and the probate court determines who shall serve as guardian of that child, even when there is one surviving parent. The probate court’s decision on a guardian may or may not be the same person you would have chosen and your assets may not be distributed in the way you desired.

The process of proper estate planning for a person with a disability is often misunderstood. It is not just a sophisticated method to avoid or reduce estate taxes due when one dies. For most families with a disabled dependent, the primary goal of planning is to ensure that the dependent receives a lifetime of adequate care and support that eligibility for governmental benefits can offer. This requires proper handling of family resources.

You and your attorney need to understand the specific needs of your child with the disability and be familiar with local, state, and federal entitlement, and welfare and sliding scale fee programs upon which your child may depend for lifetime care and support. But most importantly, you need to know about what is commonly referred to as a “special needs” trust. A special needs trust provides that the Trustees distribute funds from the trust for items not provided by the government. Under current law, a properly worded special needs trust is not considered a countable asset of the beneficiary.

As an attorney and volunteer with The Arc of Illinois and Massachusetts, I frequently review wills and trusts for members of The Arc. Nearly 90 percent of the wills and trusts that I review are drafted in such a way
that the child can either not receive
government benefits or remain eligible for
them. Often the wills are not even properly
written to avoid a guardianship of the estate.

It is unfortunate but most attorneys are not
familiar with special needs trusts. As parents
and as your child’s advocates, you need to
become familiar with the estate planning
methods or options often recommended by
attorneys and to understand the advantages
and disadvantages of each. Which method
you choose depends on the size of your
estate, your child’s needs and the
availability of a trusted and responsible
family member or friend to manage your
child’s trust assets. The two most frequently
recommended methods are “disinheritance”
and “support” trusts.

Lawyers frequently recommend
disinheritance to preserve an individual’s
eligibility for government benefits.
However, I never recommend it, even for
families with small estates. I believe that
disinheritance often offends the individual
with a disability and it is often painful for
the parent to think about disinheriting the
one child who needs their help the most. If a
parent or grandparent has a trusted relative
or friend who can serve as trustee, there is
no reason why a special needs trust should
not be used even for small estates.
Frequently parents tell me they have
disinherited their child with a disability and
plan to rely upon a gift to a sibling, who is
then obligated to look out for the child’s
interests. Such a gift is “morally obligated,”
not legally enforceable, and there is no
guarantee that the funds will continue to be
used for that person’s care and support.

Even when your non-disabled child is
extremely conscientious and reliable, many
problems could arise that are beyond the
ability of the sibling to control. For example,
the funds are considered part of the sibling’s
estate and will go to legal heirs upon the
sibling’s death, can be claimed by creditors,
or by the sibling’s spouse in the event of
divorce.

The other estate planning method frequently
recommended by lawyers is potentially
more harmful than disinheritance. Lawyers
who are not familiar with eligibility for
government benefits and who think of the
person with a disability as the “eternal
child” often draft a traditional “support”
trust. Even if this trust has what is called a
discretionary, spendthrift clause that protects
the trust assets from the child’s creditors, it
may not protect the entire trust from being
taken by the state.

The reason is that states often claim that
their limited resources are only for the care
of people with disabilities who are indigent
and unable to care for themselves. If a
beneficiary of a support trust has a disability
and is receiving government benefits, the
state may take the position that it should be
reimbursed from that trust for the cost of
providing care. Therefore, the trustee may
be forced to turn over the assets of the
support trust to the state if the state is
providing services for the person with the
disability. If your child requires services
from government programs, their trust’s
assets may be jeopardized in a support trust.
Moreover, your child’s right to support from
such a trust may jeopardize eligibility for
certain important government benefits such as Medicaid. A special needs trust remains the only estate planning option that avoids the loss of assets meant to supplement your son or daughter’s life and allows the donor to preserve the remainder balance for family members or charities. A special needs trust enables your child to receive ongoing goods and services from an adequate share of your estate while still preserving the child’s eligibility for government benefits and the care and support these benefits can provide. If properly drafted, it protects the assets of the trust from liability for services which are available from the state. A properly written third party funded supplemental needs trust can be left to other individuals and/or charities upon your child’s death.

If you already have a trust and are not sure if it is a support trust or a special needs trust, look at the language in the trust document which states the primary purpose of the trust. If your trust indicates that the primary purpose is for the “care, support and benefit” of the beneficiary, then you most likely have a support trust. If your trust states that the purpose of the trust is to “supplement and not to supplant” state and federal benefits, then you again most likely have a special needs or supplemental needs trust.

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Top Ten Tips in Creating a Real Home for a Family Member with a Disability

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

Over 160 people attended the Real Homes, Real Solutions seminar sponsored by the Fletcher Tilton Special Needs Practice Group on March 19, 2011. This seminar presented legal issues, family stories and information from housing finance experts related to creating residential supports for family members with a disability. From my reflection of the seminar, I’d like to share what I consider to be the ten most important “take-away” points.

1. Future of government resources. There is no dispute that the current economic conditions facing the nation, the states and our local communities will continue. It is estimated that 45 states are expecting budget shortfalls in fiscal year 2012. The recent recession created the largest number of job losses since the Great Depression and the continuation of high unemployment figures bodes a slow and unsteady economic recovery. On the federal budget level, there will be continuing efforts to reduce the burgeoning federal deficit. Individuals with disabilities, recipients of Medicaid benefits, and others who rely on government assistance for health care will face the threat of reductions in appropriations, elimination of some benefits and a conversion to a Medicaid block grant. These threats are real. So, in planning a residential future, significant reliance must be made on private funds. While we must continue to advocate to maintain and increase federal and state appropriations as well as work toward creating more cost-effective models to use government appropriations, families must not overly rely on the hope that government resources will be the sole support of their son or daughter in the future.

2. Importance of starting early with a plan. The parents who have successfully arranged an appropriate home for their son or daughter started planning one to three years before their son or daughter moved in. I am pretty sure that they began internally mulling things over in their minds well before that. The reasons for planning early are self-evident. First, you need to develop consensus within the family about whether your plans make sense and to build an internally driven commitment within the family to keep moving forward. One very obvious trap is what I call the Get-To-It trap. These are the ideas, plans and things that need to be investigated, performed and vetted in order to move forward, but you put them on your To Do list. The problem is that many people never Get-To-It. These are the things that you’ll get to... someday. But the list grows and grows while life just happens. Covey has written about the critical importance of prioritizing those things in our life that at the moment are not urgent but which are very important. The key is to discern those things that are truly urgent and important from the crisis of the day or week that seems urgent but which is, in reality, not all that important. My advice is to schedule some quiet time on a regular basis to write out your thoughts, talk about your plans with your spouse and important other people and to conduct your due diligence. This
can be an on-going “Planning Meeting” for you and your family members with invitations going out to others on an as-needed basis.

3. **The use of leverage.** Broadly speaking, leverage is creating more power through the creative use of resources. For instance, leverage can be three or four families coming together to pool their money to create more buying power so they can purchase a home more easily together than they could on their own. Some families may have more financial resources than others while some others may have more time to contribute. Don’t minimize the value of time that may be able be to be contributed. In one successful model, two families planned an arrangement where one family purchased a house next to the other family who did not have the financial capital to contribute toward the purchase of the house. But they have something as valuable as money, they have human capital. They live next door and provide a myriad of support to the two young adults living in there. It works. Also, many retirement plans can be leveraged through a loan. Repayments must be made at a marketable interest rate, but remember, you’re replenishing your own retirement account by paying down the loan. You will need to check with your retirement plan administrator to see if this is possible with your particular plan. Finally, you should evaluate the advisability of refinancing your principal residence or taking out a home equity loan.

4. **Things change, be flexible.** Where we live depends on many factors including the location of family and friends, our work, the type of environment we choose to live in and a host of other factors. Things change. We down-size, we retire, we get divorced, etc. And major life events are often accompanied with a change in living environment. In most circumstances, real property in a trust or in a corporate real estate holding entity can be exchanged with very little difficulty so as to accommodate changes in the location of property.

5. **Identify housing dollars separate from support and service dollars.** The acquisition and regular maintenance of real estate can be budgeted and planned for in a fairly easy fashion. The source of funds to purchase may come from savings, a loan from a retirement account, a gift from family members, proceeds from a home equity loan, etc. The regular carrying cost of the home can be paid from anticipated rental income, a planned escrow account or other anticipated revenue. I suggest you consider creating an annual budget for estimated housing costs as a planning tool. Two important sources of government funding for residential support for individuals with disabilities are the Section 8 voucher program and the Alternate Housing Voucher Program (AHVP). Both programs are administered through housing assistance agencies and local housing authorities. Applications for rental vouchers can be obtained and filed at local housing authorities. Even with an anticipated long waiting list, I suggest that an application be filed if there is a tangible possibility of your son or daughter moving out of your home. Under federal regulations governing the use and administration of Section 8 housing vouchers, a person with a disability who has been granted a voucher is entitled to a reasonable accommodation in how the voucher is used. This means that the customary “arms-length” requirement between landlord and tenant can be modified. So, a family owned or controlled rental unit can be leased to a family member with a disability who has a voucher. In some circumstances, a special needs trust can be the landlord and the beneficiary of the trust can be the tenant.
6. Know the support and service needs of individuals. A complete understanding of the service and support needs of each individual must be arrived at as part of the planning process. While this may seem obvious, there is one general tendency I’ve noticed over the years. Parents often overestimate their son’s or daughter’s daily living skills. Often, parents discount the value of a regular routine, the presence of familiar family members and the often overlooked presence of verbal and non-verbal cueing that is natural in a home environment. It may be worthwhile expense to retain the services of a qualified professional to assist you in accurately evaluating the level of services and supports your son or daughter as well as other prospective residents will need when they move into their new home. Accurately assessing the service and support needs of each individual is essential in estimating the anticipated costs of meeting those needs through appropriate staffing.

7. Identify support and service dollars. Obviously, if your son or daughter and other prospective residents are eligible for adult services from a state agency, you should speak with the appropriate person assigned to his or her case about your intentions. This person can be helpful in providing a realistic expectation about prioritization and allocation of resources. Also, personal care assistance (PCA) funded through the Division of Medical Assistance can be a source of support dollars. A determination of whether PCA is appropriate and the extent of the PCA support should be made as soon as possible. Finally, each resident’s Supplemental Security Income (SSI), Disabled Adult Child (DAC) benefits and other recurrent monthly income will be available to fund a portion of the supports to be provided. It is customary that seventy-five (75%) of the recurrent monthly income of each resident be paid as a form of a service fee. Also, for many families, privately paying for services and supports has become a daunting but necessary reality.

8. Importance of good advisors. The activities of maintaining a home for a son or daughter with a disability can involve, for instance, the purchase of real estate, creating a landlord/tenant relationship, having service and supports being provided on a regular by paid staff, maintenance and upkeep, etc. An attorney should be involved in many of these areas including selection of the appropriate legal entity to own the real estate, creating sensible service agreements for settings that are non-DDS or non-DMH regulated, understanding and complying with applicable labor/employment practices, identifying potential sources of liability and taking steps to minimize and/or avoid such liability is essential. The skills and talents of experienced staff who can manage a residential setting can be a valuable asset. There are a number of highly skilled administrators with years of experience in managing residential services and supports for individuals with disabilities available to serve either on a short-term consulting or long-term management fee basis. Of course, having a reliable handyman, plumber, and electrician on speed-dial can save time and lower your blood pressure when the inevitable yet unexpected housekeeping crisis hits.

9. Integration of the housing model into your estate plan. You must plan for how the home will be managed when you are unable to be involved due to death or disability. A comprehensive, special needs plan is an essential part of developing a home for your son or daughter with a disability. The fundamental documents must provide for the distribution of assets to the appropriate persons.
and trusts in the proportions desired. Durable powers of attorney with critical Medicaid planning language and health care proxies are essential. The use of a special needs trust to hold assets for the benefit of a son or daughter with a disability to pay for future services and supports is the centerpiece of this plan. These essential documents must be coupled with a realistic financial plan adequate to provide for supplemental services and supports throughout the lifetime of a son or daughter with a disability.

10. **Important personal qualities: patience and persistence.** There is no cookie cutter approach to developing an effective and successful home for your son or daughter with a disability. It is easy to get disillusioned because solutions are slow to develop. There are many moving parts. Some dead-ends. The parents I have had the privilege to work with on these types of situations have demonstrated an enormous amount of patience and persistence. They share a common characteristic that expects more from themselves than from any one else, including the government. There is also a sense “I know best” and “I’m going to keep trying”. These personal characteristics of patience and persistence imbued with a sense of optimism are important to move from the vision of a home to a real home.