Advice and Guidance for the Financial Planner Advising Parents of Children with Life Long Disabilities

By Theresa M. Varnet, Esq.

Parents and families providing for life time care of persons with disabilities will gain great peace of mind if they take the time to plan for the special needs family member's future care while they still have the health, time and energy to do so. Planning is more than just having a will and a special needs trust in place. This article will provide practical advice and recommendations for parents, siblings and grandparents who are concerned about where their family member challenged with a disability will live when the primary caregiver dies or how the family's resources can be used to maximize the quality of life their family member will enjoy.

THE ROLE OF THE FINANCIAL PLANNER IN LIFELONG PLANNING FOR PERSONS WITH SPECIAL NEEDS

The financial planner is well able to assist so called "typical families" plan for their life-long needs. Providing a financial safety net in the event a parent dies prematurely or becomes disabled and is unable to work, saving for a home, providing adequate funds for a child's college education, a child's wedding, and of course, for the parents' retirement are all within the expertise of the standard financial planner. However, it is the rare financial planner who is knowledgeable about the extraordinary financial planning needs of families with a member who is disabled and may be unable to provide for him or herself.

The special needs family requires all of the expertise that a financial planner offers to typical families plus the added need to plan for their disabled child beyond their own lifetimes. A special needs child may live 20-30 years beyond the lifetime of his/her parents. Most parents of children with special needs are overwhelmed by the day to day care and concerns of raising a special needs child. With their thoughts focused on getting through 'today', they often fail to plan for their child's future when they are no longer able to provide for their child. The planner who is capable of steering families of a special needs child in the right direction at various times in their child's life, will earn the trust and respect of all family members. The following practical advice is offered to special needs financial planners to assist them in advising their special needs clients from birth to adulthood.

Here is some information that financial planners can share with clients advising them of some steps they can take at various stages of their child's life.

BIRTH TO EARLY CHILDHOOD

The parent of a young child who is first diagnosed with a disability or special need is often in grief for the loss of the 'perfect' child they expected to have. In addition to feelings of grief and sadness, the parent(s) may be fearful of the unknown, overwhelmed with the medical needs of the child, and feeling at a loss as to how to cope with their child's disability.

At this early stage, information is power. Families need to become knowledgeable about their child's specific disability and health issues. Joining support groups such as National Association for Down Syndrome, The Arc, National Alliance for Mentally Ill, Autism Society, etc., will provide families with cutting edge information about their child's disability.

The financial planner working with a competent special needs attorney can assist families in these early stages by discussing the typical insurance needs as well as work with grandparents and/or siblings who want to help provide for the special needs child's future. Parents should be encouraged to write a will which includes a special needs trust and identifies an advocate/guardian for the young child if needed. Grandparents can be encouraged to revise their own estate plans to protect the young grandchild's future eligibility for government benefits. By signing a power of attorney for property with specific transfer of asset language, the grandparent may be able to preserve his/her estate for the special needs grandchild should the grandparent later require long term nursing home care for him/herself. Grandparents also need to change the beneficiary designations from the typical 'descendents per stirpes' to identify a special needs trust as the beneficiary for any share distributed to a special needs grandchild. The planner may also want to meet with other family members such as adult siblings who may want to provide for their special needs brother or sister. Even your client's siblings may want to provide for his/her special needs niece or nephew. I have found that extended family often want to help but do not know what to do and as a result do nothing. The special needs planner who looks at full family participation may not only expand his/her practice but provide a critical need to a specific family who want to help but need direction.

The financial planner or attorney who provides the family with information about their child's disability and can give examples of how proper planning enriches the life of other disabled adults will earn greater respect from the family. This earned respect will go a long way in the family accepting financial recommendations from the planner. As a special needs attorney, I feel it is important to belong to a number of different organizations and subscribe to a number of newsletters to stay informed about different disorders. I also keep the last few issues of newsletters on file or journal articles on certain disabilities so if I meet a client with a child with a low incidence disorder such as Tuberous Sclerosis, Prader Willi Syndrome or William's Syndrome, I can hand the client something to take home with them. Once the client feels you are genuinely interested in his/her child, trust is easier to establish and the client and his extended family will be more open to the financial planner's recommendations.

MIDDLE SCHOOL OR EARLY TEEN YEARS

If a financial planner is meeting with a family for the first time, all of the above advice remains pertinent. In addition families need to be advised of the need for getting their child's financial situation in order. If the child has received U.S. Savings bonds as gifts, has funds in an UTMA or UGMA account, it is now time to think about spending down this money and/or transferring to a qualified special needs trust. (This type of trust is often referred to as an "OBRA d4A" trust or as a "payback trust".) If the child has substantial funds in his/her name, the planner may want to investigate using the funds for a single premium survivorship policy. If the child's funds are used to pay the premium, the life insurance policy must be owned by the OBRA trust. Despite the need to include a payback clause in the OBRA trust, this may be a prudent way of leveraging the child's funds so that there are more funds available for the child should his/her parents die prematurely.

If a child is just five or six years away from receiving SSI, the financial planner may want to discuss with the parents and/or grandparents the purchase of a second to die life insurance policy. If the parent is not in the financial position to pay the premiums, the grandparent(s) may be willing and able to pay the premiums. The grandparents do not have to make a commitment to pay long term on the policy but only until the disabled grandchild becomes eligible for SSI. Once the child turns 18 and the parent's income/resources are no longer deemed, the disabled child often becomes eligible for SSI. If the parent charges the child for his/her fair share of food and shelter, the parent then has a new source of funds to continue paying the premium for the survivor life insurance premium.

The financial planner may also want to remind the grandparents of the little known exception to the transfer of asset rules that allows a parent or grandparent who requires long term nursing home care to be able to transfer his/her assets to a qualified special needs trust (commonly referred to as an OBRA trust or a "c2Biv" special needs trust. If a grandparent has a modest estate and may have to spend his/her assets down in order to qualify for Medicaid, the use of a qualified special needs trust is a viable way of preserving assets for a disabled grandchild. If the grandparent is no longer competent to knowingly gift his/her money to a qualified special needs trust, the only way this type of gift can be made is if the grandparent signed a power of attorney which includes Medicaid gifting powers, while he/she was still competent. This special power indicates his/her intention to preserve his/her assets for the grandchild in an OBRA trust in the event long term nursing home care is ever needed.

AGING OUT OF HIGH SCHOOL AND NAVIGATING THE MAZE OF ADULT SERVICES

The financial planner may want to tickle his/her file to remind him/herself to make an appointment to meet with his/her clients when the disabled adult child is about to turn 18. Many parents are not aware that their adult child may be eligible for SSI and Medicaid at age 18.

It is not uncommon for parents to assume their income and assets are counted for as long as the child lives at home or at least until the age of 21. They will be extremely grateful to a financial planner who provides them with information about SSI and/or Medicaid prior to the child tuning 18. The receipt of SSI cash benefits also presents an ideal planning opportunity for those families who did not have grandparents willing or able to pay the premiums on a survivorship policy. Now may be the ideal time to approach the family with the novel idea of using the child's newly received SSI payments to provide for his/her future. If the survivorship policy is payable to a third party special needs trust, one cannot pay the premium on a survivorship policy directly from SSI funds. However, the parent(s) can use the funds to reimburse themselves for the portion of food and shelter s/he provides to the now disabled adult child to pay the premium. It has been my experience that we are all capable of spending all income we receive. If the financial planner approaches the parents to use the newly acquired funds on a premium payment before they get used to spending it on other luxuries or expenses, the future of the special needs child will be greatly enhanced by the purchase of the survivorship policy. It becomes an issue of what you spend the extra money on and a financial planner will be missing a unique opportunity if s/he doesn't plan to revisit this issue with families when the adult special needs child begins to receive SSI.

(As a reminder, there are two types of special needs trusts. The first is commonly referred to as a third party special needs trust. This type of trust is created by a parent or grandparent and when the special needs beneficiary dies, the funds are distributed to other family members or charity. The second type of special needs trust is called a qualified special needs trust or an OBRA d4A or C trust or a payback trust. This type of trust can own a life insurance policy made payable to the trust but the trust must provide for a payback for the cost of all Medicaid funded services to the state which provides them. The third party special needs trust is the preferable trust as it does not require a payback clause. A handout on each type of trust is enclosed for the financial planner to share with families when advising them of their options).

Parents also often believe that if their child is covered under their private health insurance, s/he is not eligible for Medicaid. Parents who can retain health insurance coverage for their adult disabled children should be encouraged to do so. In most cases, having private coverage will provide the child with a higher quality health care. Because of its low reimbursement level, many doctors will no longer accept Medicaid. The child with private health insurance will have a greater choice in finding health care providers. However the Medicaid can be beneficial to the family in paying part if not all of co-payments. This is especially true if the child is taking a number of medications or if a medication s/he is receiving has a high co payment. There are also a number of services that private insurance will not cover which Medicaid may provide to the child. Having both private health insurance and Medicaid maximizes the health benefits the adult child is eligible to receive.

WHO WILL PROVIDE FOR THE SPECIAL NEEDS CHILD WHEN HIS/HER PARENTS ARE NO LONGER ABLE TO PROVIDE CARE?

Planning for one's child's future is often an overwhelming task. It is the unusual parent who can approach this task alone. I always recommend the 'team' approach in planning for the adult child's lifelong care needs. The financial planner that may be aware of the programs available to assist disabled and low income persons to live independently is a valuable member of this team or may be able to point the parent toward a professional who can advise them in this area. Public funding for long term residential care for persons with disabilities is extremely scarce since states started cutting back social service programs. This speaker is not aware of a single state that hasn't initiated budget spending cuts in a number of areas that affect the ability of a person with special needs to live independently of his/her family. With the shrinking of public dollars, families need to plan privately now more than ever.

A special needs financial planner may want to become familiar with housing specialists in his/her state who can advise parents of the existence of and eligibility requirements of generic programs that assist disabled and low income persons to live independently. Due to shrinking dollars, the only way many individuals with disabilities can afford to achieve residential independence may be through the use of public/private funding. Such an arrangement is often referred to as a 'Public/Private Partnership". Many states are encouraging these partnerships and have developed new models of care that reflect the use of public and private monies.

The financial planner can work with families to assess their current financial situation and see what each family is able to afford in discussing a public/private partnership to enable their son or daughter to move out of their home. Models such as Supported

Living, Supervised Living, Shared Living, Home Sharing, Adult Foster Care and more have sprung up in recent years. State agencies are becoming more flexible in providing Community Supports and allowing the Medicaid Waiver Program the ability to cover the cost of these 'in home' supports. States are no longer limiting Medicaid funded to group homes, nursing homes or congregate care living arrangements.

The financial planner who is knowledgeable of generic poverty programs such as Section 8, food stamps, fuel assistance, low interest and low down payment loan programs available for persons who are poor, will be able to assist the families in developing a housing budget which maximizes the generic housing funds available then preserve the parents' private dollars to fill in the gaps. Developing a housing budget will also enable the financial planner to determine the amount parents need to set aside in a 3rd party special needs trust to enable the adult child with the housing option of his/her choice. Serving as a member of the team which helps families navigate the various state agencies and public programs still available will provide the special needs planner with an additional opportunity to fine tune and update the financial planning needs of their client. The special needs financial planner is a critical member of the team and can help the family focus on the financial issues involved with planning for their child's future.

Theresa M. Varnet
P: 508.459.8091
F: 508.459.8391
E: tvarnet@fletchertilton.com

Fletcher Tilton PC
Attorneys at law

THE GUARANTY BUILDING
370 Main Street, 12th Floor
Worcester, MA 01608
TEL 508.459.8000 FAX 508.459.8300

THE MEADOWS
161 Worcester Road, Suite 501
Framingham, MA 01701
TEL 508.532.3500 FAX 508.532.3100

CAPE COD
171 Main Street
Hyannis, MA 02601
TEL 508.815.2500 FAX 508.459.8300