

Planning Strategies for Individuals with Special Needs

From Mid-life and Beyond

By Danielle Mayoras
and Matthew Joswick



Many articles in *EP* explore special needs trusts and the wonderful benefits that they provide to both parents and individuals with special needs who are on government benefits. When a parent leaves an inheritance over \$2,000 to an individual with special needs, the inheritance is actually a gift to the government because it eliminates that child's qualification for government benefits. The use of a special needs trust eliminates this disqualification because the inheritance is not left to the individual with special needs, but rather to his or her trust. As a result, the individual maintains his or her government benefits and receives an inheritance. These trusts provide peace of mind to the parents and an additional fund for the individual with special needs. The special needs trust answers questions, such as 1) *Who will care for my loved one with special needs when I die?* 2) *How will my loved one's extras be paid after I pass away?*

This article, however, goes beyond the basic special needs trust and also focuses on the planning for an individual with special needs from mid-life and beyond. In addition to the general con-

cerns that parents of children with special needs have, parents also worry about the long-term care costs of their loved ones. Specifically, what if the individual outlives his or her parent and needs long-term care? What if the parents are not around to provide long-term care? How will long-term care costs be paid?

The statistics show that it is likely that an individual with special needs will require some type of long-term care. There are currently 1.2 million Medicaid enrollees who have disabilities who are either receiving acute care or long-term care. There are several different long-term care options including home care, assisted living, adult foster care, and nursing homes. Each of these will be addressed separately as the article continues.

Home care is health and supportive care provided to an individual in his or her own home by a licensed medical professional. The advantages are obvious; your loved one receives care in the comfort of his or her own home. This ensures more privacy for your loved one and also allows the family to better monitor the quality of healthcare that a loved one with special needs is receiving.

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Assisted living facilities are a middle ground between home care and nursing home care. Typically, residents of assisted living facilities require help with their activities of daily living, but do not need skilled nursing home care. The advantages of receiving care in an assisted living facility are clear—the environment is more residential and less restrictive with a greater emphasis on privacy and autonomy.

With the average hourly rate for home care at \$19.18 per hour, and the average cost of assisted living at nearly \$40,000.00 per year, receiving care in these environments will be cost prohibitive for most families. Some long-term care alternatives to these high costs are Adult Foster Care and nursing homes.

Adult Foster Care (AFC) is a licensed, sheltered living arrangement for adults with special needs who are unable to live alone. AFC homes provide five basic services: room, board, supervision, protection, and household services (laundry, cleaning, etc). Additionally, adult foster care homes may provide the following services: assistance with dressing, personal hygiene, and/or eating; transportation to appointments, senior centers, shopping, or activities; medication reminders of administration; and assistance with money management.

Typically, there is a minimum room and board payment made to providers per month, which is set by the state. This amount is typically equal to the monthly income that the adult with special needs receives in governmental benefits. Adult foster care may be a cost-effective alternative to nursing homes or larger assisted-living facilities. For many individuals with special needs who need long-term care, adult foster care is appropriate medically and financially is a good long-term care option as well.

On the other hand, nursing care facilities are places of residence for people who require constant care and assistance with their activities of daily living. Residents include both the elderly and individuals with special needs. The numbers are startling—the average cost of nursing home care in the United States exceeds \$77,000.00 per year and is expected to reach \$190,000 per year in 2030. Furthermore, almost 56 percent of nursing home residents spend at least one year in the nursing home, with another almost 26 percent spending at least three years in the nursing home. Many parents wonder how their loved one with special needs will be able to afford it.

One way is to qualify your adult child with special needs for Medicaid. Medicaid is a state administered program that pays for long-term care costs if certain eligibility requirements are met. Although this is a federal program, each state has its own guidelines regarding eligibility and services. Therefore, it is critical to consult with a special needs attorney who is familiar with the specialized Medicaid laws in the state where your loved one resides.

Certain requirements must be met to qualify for Medicaid. These may include your age; whether you have a disability, are blind, or aged; your income and resources; whether you are a United States citizen or a lawfully admitted immigrant. The rules for counting your income and resources vary from state to state and from group to

group. There are special rules for those who live in nursing homes and for children with disabilities living at home.

A single individual who resides in a nursing home may own certain assets, which Medicaid views as exempt assets, and still qualify for Medicaid. For example, in the State of Michigan, those exempt assets for Medicaid eligibility are as follows: home (with certain restrictions); car; personal property; burial plot and burial space items; funeral contract worth up to \$11,072.00; life insurance with face value of \$1,500.00; \$2,000 in cash assets; assets that are in a special needs trust, an OBRA (Omnibus Budget Reconciliation Act) Trust, or a Pooled Income Trust; and immediate annuity.

All other assets are countable, and an adult child with special needs will not be Medicaid eligible until those assets are spent down or converted into one of the above exempt assets.

You can ensure that your child with special needs qualifies for Medicaid upon your death by planning ahead. By completing a full estate plan, parents are able to place the adult child's portion of their inheritance into a special needs trust. This trust allows the adult child to maintain government benefits as the trust is an exempt asset under Medicaid guidelines. When the parents create their own estate plan, their revocable living trust will provide the inheritance, for the benefit of their child with special needs, to be funneled into the special needs trust.

The special needs trust has a trustee, who is responsible for administering the trust and ensuring that the adult child's needs are met. Assets in a trust of this nature are not countable, and in the event that the child requires long-term care and needs to qualify for Medicaid, these trust assets will be preserved for the adult child's benefit. A trust of this nature can be used for most any item the adult child may need with the exception of food and shelter. For example, the trustee can purchase clothing, an automobile, electronic equipment, furniture, fitness equipment, funeral expenses, vacation and travel costs, vocational programs, therapy, personal care items, and much more. The trustee can also use the funds from the trust for non-reimbursed medical expenses.

While government agencies recognize special needs trusts, there are strict rules, and it is critical that you work with an experienced special needs attorney to draft the trust. We have reviewed countless special needs trusts that do not comply with Social Security Insurance and Medicaid Rules. If the funds are used for food or shelter, however, then there is the potential that the adult child's governmental benefits may be reduced or eliminated. With respect to shelter, your child can use the money to purchase a home but cannot use the money for rent. In fact, one wrong word or phrase can make the difference between an inheritance that benefits your child and one that causes your child to lose the many services, assistance, and benefits available.

In the event that the parents pass away without having the proper estate planning in place, there are still planning strategies that can be implemented to preserve the inheritance of the adult child with special needs, allowing the adult child to maintain or qualify for government benefits. The inheritance can be placed into an OBRA dis-

ability payback trust or into a pooled income trust. These trusts provide the same protections as the above discussed special needs trust with one important difference—both of these trusts have a provision that require the assets to be used for specific purposes after the death of the adult child with special needs. The OBRA trust requires that in the event there are any funds remaining in the trust at the death of the adult child with special needs, Medicaid is paid back for any services rendered up to the full amount of assets in the trust. The pooled income trust, run by a non profit organization, requires that the organization be the remainder beneficiary of the trust.

Something else to keep in mind is the possibility of your loved one with special needs executing durable powers of attorney. If your adult child with special needs is competent, then he or she can execute durable powers of attorney. There are two types of durable powers of attorney: financial durable power of attorney and medical durable power of attorney/patient advocate designation. By executing a financial durable power of attorney, your child appoints an attorney-in-fact to handle his or her financial affairs in the event that he or she is physically or mentally unable to do so. For example, this may include banking, real estate, signing tax returns, hiring and firing agents, and commencing litigation.

The medical durable power of attorney/patient advocate designation addresses all of your loved one's medical decisions, including residential placement, surgery and treatment, and daily medical decisions. If your adult child with special needs is able to execute durable powers of attorney, this will generally eliminate the need to go through the probate court system to obtain a guardianship or conservatorship. These documents cannot be executed by your child until he or she is an adult and is 18 years of age. As probate court can be expensive (legal fees and court costs), burdensome (annual report requirements and multiple

trips to court), and time consuming, it is highly advisable that if your adult child with special needs has the requisite capacity to execute legal documents that they do so. Most importantly, he or she would be able to maintain control of his or her financial and medical decisions.

We know that every parent's greatest worry is what will happen to their loved one after they are gone. With the proper planning, there are government programs for receiving long-term care after you are gone and receives an inheritance from you that does not disqualify him or her from government benefits. Estate planning is always important to do; however, when one of the beneficiaries is a loved one with special needs, the planning becomes critical.

It is important to note that the laws are constantly changing, and it is vital that concerned parents consult with an expert. If you would like more information, a referral to an attorney to assist you, or training and workshops on this topic, you can contact The Center for Special Needs Planning at 877-PLAN-PLUS. You can also subscribe to the Center's bimonthly e-letter at www.thecenterforspecialneed-splanning.com to keep current on the laws.

This article provides general information concerning a variety of legal topics. It is not intended to be a legal opinion and should not be relied upon as legal advice. Legal advice should not be given without investigation of your particular circumstances. •

Danielle Mayoras is an Attorney and the Director of Community Education with The Center for Special Needs Planning.

Matthew Joswick is an Attorney and a Counselor with The Center for Special Needs Planning.