

# PLANNING CONSIDERATIONS FOR PARENTS OF CHILDREN WITH DISABILITIES

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## I. Importance of Estate Planning

Raising any child to adulthood is full of challenges, but for parents of children with disabilities, concerns about their sons' and daughters' futures are magnified. Some people with developmental disabilities will have a high degree of independence and others will need one or more advocates looking out for their interests all of their lives. With adequate planning these children can lead a productive, satisfying life, but failing to plan could leave the child in a precarious financial situation. Questions to consider include: where the child will live, how he or she will receive needed support, and how the costs will be covered.

“Estate planning” generally refers to the steps individuals or couples take to direct what will happen to their money and other assets after death. Most people want to direct how their money or assets will be distributed, minimize taxes, and choose who will care for their minor children or their adult children with disabilities. An estate plan requires a person to ensure that important supports will be there for the child to help him or her have a happy and productive life. Parents may name people who will provide support for an adult family member with a disability who needs assistance. This may be accomplished by setting up a plan that includes a will, letter of intent, supplemental needs trust and/or other pertinent documents.

Lack of planning can result in undesirable outcomes. For example, state laws dictate that if a person dies intestate – without a will – surviving children will directly inherit money and other assets. If a child with a disability receives SSI and Medicaid (or could qualify for these benefits when he or she becomes an adult), that child will lose those benefits and have to use the inheritance for daily living costs and health care. Few inheritances are large enough to cover these costs for long. Thus, the needs that the inheritance was intended to meet could go unmet.

Families should seek an attorney who understands not only estate planning issues but who also is knowledgeable about government benefits and understands, and is sensitive to, the needs of people with disabilities. Parents who have a child with a disability may encounter special issues related to their family member's care and support. An estate plan enables parents or others currently providing support to set up alternatives in the event something happens that will make them unable to continue in a supportive role. These issues may range from obtaining public benefits, communication devices, education, employment, housing, and transportation to ensuring such things as favorite foods, recreation and visits with friends.

Government benefits – both financial assistance and health care benefits – are very important for many people with disabilities. Many parents are concerned about leaving money to their child with a disability because they fear that the child will lose public benefits such as Supplemental Security Income (SSI) or Medicaid. On the contrary, the fact that someone is receiving benefits should be an incentive to begin planning. A plan can ensure that the child keeps needed benefits and is able to use the additional assistance from family to purchase items that government benefits do not cover to enrich his or her quality of life.

## **II. Wills**

### **A. What is a Will?**

A will is a legal document that stipulates a person's wishes and instructions regarding who will receive his or her money, property and other belongings. The three legal requirements for a will are that the testator (the person who makes a will) create a writing of his or her wishes, that the writing be signed, and that it also be witnessed. The will should name the beneficiaries, those persons who will receive the assets in the estate after the testator's death. It should also name a "personal representative" (formerly called an "executor") who will handle the estate and make sure that it passes to the beneficiaries as specified in the will. If someone dies without a will, or the person named in the will is unable to serve as the personal representative, then someone who is willing to serve may petition the court to be appointed personal representative. The court will consider the person's relationship to the deceased individual in making the appointment.

A will can serve some other important functions, such as naming a guardian for minor or disabled children after the death of both parents. A parent who has been named as guardian of his or her adult child with a disability should also name a guardian to take over after his or her death. Unless there are unusual circumstances, the court will comply with the parent's wishes.

Even if the parent has not been legally appointed as guardian, it is wise to specify in a will who will take on the guardianship role for the disabled adult child upon the parent's death.

A will can also state that a trust will be created for a disabled child or someone else and that it will take effect when the parents die. This option is especially important if the child receives government benefits. A supplemental needs trust can receive that child's share of the estate, so that the child's benefits will not be jeopardized.

## **B. Creation of a Will**

A will is a complex document that should be done in consultation with a lawyer to ensure that it is made in compliance with legal requirements and to assure that it is not invalidated. This is especially true when the will is made for the protection of a child with disabilities. An improperly prepared will could inadvertently make a child with disabilities ineligible for needed financial and health care benefits. An attorney should be chosen who is experienced in protecting the interests of families with special needs children.

The attorney should meet with the testator to discuss his or her wishes as to a personal representative, beneficiaries, guardians, distribution of the estate, and any other stipulations that may be included in the will. A will may be written to include a trust, when the individual has a large number or variety of assets, or other complex issues.

After the meeting, the attorney drafts the will and reviews it with the testator to make sure that all the desired provisions have been covered.

In order to sign, or "execute," a will, a testator must be competent to understand what assets he or she owns and to name the beneficiaries who will receive those assets. In most states, the will must be signed in the presence of two witnesses, who must then sign the will in the presence of the testator. Wills can be revoked or changed, as the wishes or needs of the family change.

## **C. What Assets Does a Will Cover?**

When a person dies with assets in his or her name alone, those assets usually become part of the "probate estate" and are distributed according to the person's will. The named personal representative will open the probate estate and file the necessary documentation with the Register of Wills in county where the decedent resided. The estate will have to be kept open for a certain period of time, usually six to nine months.

During that time, the personal representative must determine the exact value of the assets, notify beneficiaries and creditors that an estate has been opened, and keep an accounting of

all estate transactions for the Register of Wills. When all probate requirements have been met, the estate may be distributed to the people (or trusts) named in your will. Assets subject to this process are called “probate assets.”

Assets that are not subject to this process are called “non-probate assets.” These are assets owned by the decedent while he or she was alive, but that are distributed to others automatically upon death, rather than through probate. Examples of non-probate assets are joint bank accounts, life insurance, retirement plans, annuities, and property owned by a living trust (described in the next section). Any assets owned jointly with another person will pass to him or her at the time of death.

If a jointly-owned asset is titled as “joint tenants with right of survivorship” or “tenants by the entirety” (for married couples only), the asset will pass to the surviving person, without becoming part of the probate estate. By contrast, if assets are owned as “tenants in common” with someone else, the decedent’s share will become part of the probate estate upon death, rather than passing to the joint owner.

With life insurance or retirement plans, the named beneficiary will receive the assets upon the testator’s death. Non-probate assets do not become part of the probate estate and are not controlled by the decedent’s will. *For this reason, it is important to name beneficiaries and make sure that the estate plan covers non-probate, as well as probate assets, so the passing of the non-probate assets is consistent with the estate plan.*

Steps may be taken as part of the estate plan to avoid the probate process and keep control of the assets in the family. However, some steps required to avoid probate will limit the testator’s ability to make decisions regarding assets. For example, a father may want to retitle a savings account so that it is co-owned by him and his daughter, intending that the account will pass to her upon his death, as a non-probate asset. However, this will give his daughter the right to withdraw money while he is alive and he will have given up a significant amount of security over his finances. In addition, if his daughter has a disability and receives government benefits, her having a co-owning a bank account could jeopardize her eligibility for the benefits. Actions that will affect how a testator’s assets will be handled during his or her lifetime and upon death should be considered carefully, with the advice of an attorney.

#### **D. What Can Happen if a Person Die Without a Will?**

A person who dies without a will and has assets in a probate estate will die “intestate” and those assets will pass by the law of “intestate succession.” Each state has an Intestacy Statute that lists who in a decedent’s family will receive the estate and the order in which they will receive it.

For example, many married individuals want their estates to go to their spouses, and to their children only if the spouse is no longer living. However, the intestacy laws normally stipulate that the estate of a married person with children, who dies without a will, are divided between the spouse and children. The intestate scheme for distributing the estate may not only be against the decedent's wishes, but may present some or all of the problems with benefit eligibility and covering the cost of care for a child with a disability.

A will enables a testator to direct who will receive assets and in what amounts, and whether a trust will be created for a child or other family member with a disability. It also provides an opportunity to choose the people who will fill important roles related to the estate, such as the personal representative, trustee and guardian (if needed). A will is often done in conjunction with a letter of intent.

## **E. Letters of Intent**

A "letter of intent" is a letter written to familiarize people with the testator's expectations for a minor child or adult child with developmental disabilities. It does not have to meet the special requirements of a will or other legal documents and is not legally binding. However, it should be coordinated with the will so that it clearly communicates information to the appropriate people, such as a personal representative, trustee, guardian, or service provider to help them make important decisions on behalf of the child.

The letter of intent should be written in plain language, rather than technical legal terms. The attorney preparing the will should review the letter to make sure that it does not contradict specifications in the will and to make sure that it is thorough and easy to understand.

The drafting of a letter of intent should be a group effort, and should include input from the child for whom the planning is done, family members and close friends. The purpose is to provide guidance to others who may provide care, support, or other assistance for the child when the parents die. Times change and it is impossible to foresee the future so a general outline of the parents' expectations, hopes and wishes may be better than rigid requirements.

A letter of intent should describe the child now and explain expectations and preferences regarding the child's future in the following areas:

- ✓ Living arrangement
- ✓ Education
- ✓ Employment or other meaningful daytime activity
- ✓ Supports and services needed in all aspects of life
- ✓ Important relationships to maintain
- ✓ Medical history, health care needs, medication, and therapies

- ✓ Abilities and needs regarding things like communication, independence in daily living and personal care, money management, and decision-making
- ✓ Likes/dislikes and preferences (e.g., social/recreational activities, religion, and foods)
- ✓ Effective ways to work with, and support, your child
- ✓ Financial information: government benefits, bank accounts, trust, life insurance
- ✓ Other “important things to know” about your child (e.g., habits, behavior, wishes)

The letter should include the child’s name and date of birth. It should contain the names and phone number of important people or agencies involved in the child’s life, including doctors and therapists; service providers; a guardian; trustee; representative payee for benefits; and people who are important to maintain relationships with. The letter should also include the location of important documents.

The letter of intent should be periodically reviewed and updated when significant changes occur. Some parents review their letters of intent around the time of their child’s birthday each year. The letter should be signed and copies should be provided to important people in the child’s life (or they should be told where to locate it).

## **F. Planning Options**

There are different ways to leave assets to a child or some other beneficiary, including naming that person in a will, or naming him or her as a beneficiary of a non-probate asset, such as a life insurance policy. If the person has a guardian of property, the guardian will be responsible for investing and managing the money. If the beneficiary has a disability that affects his or her decision-making, but does not have a guardian of property, giving him or her money directly may not be the best option.

Even if a responsible and caring guardian has been appointed, another important consideration is how the inheritance will affect the person’s government benefits. If the person is receiving SSI and/or Medicaid, even an extremely small inheritance may reduce or stop the benefits. The person can reapply for benefits after the inheritance has been spent, but in the meantime he or she must spend the inheritance for food, medical care, services or other items that the benefits were covering. This would leave the person with little or no means to meet other needs or wishes.

Another question is how to leave money to a child with a disability when the child does not have the skills to handle the money, or even if the skills are present, in a manner that will not affect government benefits? Without adequate information, some people decide to “disinherit” the child, leaving him or her nothing in the will. Unfortunately, people who receive

government benefits are living in poverty and merely surviving with bare necessities. For such people, even a modest inheritance placed in trust would improve the quality of their lives.

In some cases, parents or other family members leave money intended for a person with a disability to someone else, such as the person's brother or sister, with informal instructions to spend the money for the person's benefit. Even if the "keeper" of the money for someone with a disability used the money as intended, things could happen to take the money out of that person's control. If the "keeper" entered a nursing home, the money would be used to pay the nursing home bill and the person with a disability would not have the right to any part of it. Another possibility is that creditors would be able to take the money to satisfy claims. If the person died, the money would pass on to his or her heirs, rather than to the person with a disability.

The best way to provide for a child with disabilities is to create and fund a Special Needs Trust (also called Supplemental Needs Trust) so that a trustee will be responsible for investing and spending the funds for the child's benefit. Since the trust funds will not be directly available to the child, his or her government benefits will continue without interruption. The funds remaining in the trust after your child dies can then be left to someone else.

Planning for a child or other family member with disabilities is a complex problem. There are a variety of options that must be analyzed to determine which is best for the child, for other family members, and for the family's individual financial situation. The best way to ensure that the child's needs are provided for in such a way that the child can realize his potential is to consult with an attorney who is experienced in estate planning for children with special needs.

### **III. Trusts**

Establishing a trust provides a way to set aside money and other assets for your child's benefit – during your lifetime or after your death – without jeopardizing government benefits that may be needed. Creating and funding a trust must be done properly to assure that the family's goals are met.

#### **A. What is a Trust?**

A trust is a legal document that provides a way for someone to take care of assets, including money or property, for someone else. Trusts are not just an option for wealthy families — if set up early and planned properly, even small, regular contributions can grow into a trust fund that can greatly enhance a person's quality of life.

Trusts can be created for many different reasons. If a person with a disability cannot make responsible financial decisions, a trust can direct who will handle those decisions, including

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how to invest and spend the trust money. Some people set up trusts to avoid probate, the process followed after a person dies owning assets.

Trusts can also be created to supplement the government benefits a person with a disability may be receiving (or later become eligible for as an adult) such as SSI, SSDI, Medicaid, or Medicare, without jeopardizing the benefits. These trusts are called “Special Needs Trusts” “Supplemental Needs Trusts,” or “Discretionary Trusts,” and are used to supplement, but not supplant or replace, government benefits.

Even when a family is able to leave money and/or other assets to the child, public financial assistance and health insurance are typically still vital to cover daily living costs and medical care. The money left in trust can supplement the public benefits. Even if the SSI payment is not needed to help support the child, Medicaid will be needed to cover medical expenses, unless the child becomes employed with health benefits or the family can afford to pay for private health insurance. Assets left directly to the child that result in ineligibility for SSI will most likely also result in loss of Medicaid funding. If this occurs, the money left to the child to enhance his or her life may have to cover health insurance and support needs. These problems can be avoided with a Supplemental Needs Trust.

## **B. How to Create a Trust**

A trust is created by a “grantor” who may be the parent of a person with a disability, another family member or other interested person. The grantor or others can fund the trust, which is done by titling bank accounts, stocks, or other assets in the name of the trust.

The “trustee” is the person named to be responsible for managing the trust fund for the benefit of someone else, the “beneficiary.” In our discussion, the beneficiary is the person with a disability. The grantor may serve as trustee while alive or name someone else.

Trusts are usually created by a will or “trust agreement.” They name the grantor, trustee(s), and beneficiary, and tell the trustee(s) how money should be spent for the beneficiary. Trusts created by a will are called “testamentary” trusts and become effective upon the testator’s death. A will can include all the information needed to direct where the estate will go upon death, including language setting up a trust and stating which assets will be owned by the trust. Terms of the trust can be changed any time a will is updated. However, after death, the trust terms cannot be changed and the trust will be created and administered using the language in the will.

Trusts that take effect while the testator is alive are called “inter vivos” trusts or “living trusts” and are created by a trust agreement. The trust agreement names the trustee and beneficiary,



tells the trustee how to spend the trust funds, describes what will cause the trust to end and who is to receive the trust funds when it ends, and includes other information necessary to maintain the trust. A living trust can be funded throughout life, either all at once or a little at a time. In addition, the will can specify that some or all of the estate will be used to fund the living trust after death. Other people can also make contributions to the trust while they are alive or upon their deaths, through their wills.

### **C. Revocable versus Irrevocable**

Living trusts can be “revocable” or “irrevocable.” A revocable trust is one that can be changed or terminated at any time during the lifetime of the grantor of the trust, as long as he or she has the mental capacity to make the changes. The assets in a revocable trust are still considered to belong to the grantor, since that person can regain possession of them. A revocable trust can provide flexibility when the grantor’s situation changes due to disability, health, job status or other circumstances.

An irrevocable trust is more permanent because it cannot be changed or revoked. When assets are transferred into an irrevocable trust for someone else, they cannot be taken back and are no longer considered the grantor’s assets.

Trusts are very complex legal instruments, but can be very useful tools in setting up an estate plan. An attorney experienced in the field of trusts and estates, can help determine whether a revocable or irrevocable trust is appropriate, considering issues such as tax planning, protection of assets, long-term care planning, and probate issues.

### **D. Special Needs Trust**

If a person who is eligible for means-tested government benefits (e.g., SSI and Medicaid) directly receives money or other assets, through a gift, inheritance or in some other way, and the additional assets put the person over the total allowable asset limit, he or she could lose benefits. If this occurs, the individual typically must spend the assets until they are below the asset limit and then re-apply for benefits. Sometimes, people with disabilities have housing, medical or other personal expenses that are so high that they spend the additional money very fast. A properly worded and administered Special Needs Trust avoids this problem. The individual may also create a “payback trust” or join a “pooled trust” with his assets.

If a gift or inheritance is paid to a Special Needs Trust, rather than directly to the child, the loss of benefits can be avoided. Instead of the money being spent on living and/or medical expenses, the gift or inheritance can be used to improve the child's quality of life. Extra items that such a trust might cover include electric wheelchairs, communication devices not covered by insurance, computers, vacations, visits to and from family, and other personal needs. The trustee must be careful to spend the trust funds on the beneficiary's behalf, because expenditures for items that are covered by public benefits may jeopardize the beneficiary's eligibility for those benefits. Like most trusts, Special Needs Trust vary widely and range from relatively simple planning tools for managing modest sums of money, to intricate agreements comprising only a single piece of a complex estate plan. Special Needs Trust (SNTs) can be divided into three categories: (1) SNTs created and funded by someone other than the beneficiary; (2) SNTs funded with a disabled individual's own assets; and (3) pooled SNTs.

### ***Trusts Created and Funded by Someone Else***

A trust that is created and funded by someone for the benefit of person with a disability is often called a "third-party SNT." With a third-party SNT, the assets can go directly to the trust and never be owned by the beneficiary. Because the SNT will own the assets, the beneficiary will not become ineligible for government benefits. The trust funds can be used for the individual's benefit until his or her death, when any assets left in the trust will pass to the individuals named in the trust agreement or will.

An attorney must determine the exact provisions for the SNT, considering the parents' and child's needs and desires, the amount and type of benefits the child is receiving, the eligibility requirements for benefits, and the kind and amount of assets available to place in the trust.

### ***Trusts Funded with Funds Belonging to a Person with a Disability***

Occasionally money is unexpectedly paid directly to a person with a disability rather than into a trust. Examples of such a payment might include an inheritance from a family member, life insurance proceeds, or a personal injury settlement. Direct receipt of such funds or property in any amount might cause the loss of benefits. A planning option can be used to help set aside some, or all, of the money for supplemental needs and allow the person to reapply for benefits quickly.

When the individual with a disability receives a sum of money or property, certain people (the individual's parents, grandparents, guardian or the court) can create an SNT for the individual. The trust must have special language that guarantees that after the beneficiary dies, the remaining trust funds will be used to pay back the state for services paid for by Medicaid (including health care and community services). This type of trust is called a "payback trust," "OBRA trust," or "d4A trust". The state regulators must approve all payback trusts to make sure that they meet the appropriate legal standards. After the state is paid back, the assets left in the trust can pass to the people chosen by the grantor.

## **E. Trust Considerations**

Special Needs Trusts are only one type of trust and there are many variations that can be described by an attorney experienced in this area of the law. Planning considerations include decisions about whether the SNT will become effective while the grantor is alive or take effect upon his or her death, whether it will be funded with the beneficiary's assets or someone else's assets, how much discretion the trustee will have and who will serve as trustee.

## **F. New Trust Legislation 2006**

Placing a home in a special needs trust for a loved one with a disability is a good way for parents, grandparents or others to contribute to the future of their family member and to ensure that he or she can live where happily in a home of their own where support can be provided. Families that leave a house in a Special Needs Trust are typically concerned about having adequate money in the trust, either initially or over the long term, to cover the cost of major repairs and upkeep on the home. Careful planning can address these concerns.

## **G. Estimating How Much Money Is Needed to Fund a Trust**

There are many cost considerations that must be addressed in estimating a child's annual supplemental needs. Sometimes it is not possible to pay for all of the child's needs through the trust, but careful planning can help a family to prioritize and achieve the important goals.

Some costs that should be considered are:

- ✓ Educational or vocational expenses
- ✓ Costs for living supports and advocacy services that are not otherwise covered
- ✓ Equipment and assistive technology (e.g., wheelchairs, communication devices, computers)
- ✓ Medical and dental expenses not covered by government benefits
- ✓ Expenses related to the upkeep and maintenance of a home
- ✓ Miscellaneous emergency reserves
- ✓ Expenses related to hobbies, vacations, recreation, and seeing friends and relatives

- ✓ Other items like TVs, stereos, and furniture (often you can avoid affecting government benefits by having the trust own these items and allowing the beneficiary to use them)
- ✓ Other personal expenses

The estate plan will be based on estimates, since it is impossible to anticipate all future needs. Even so, the estimates of the child's needs and potential costs are useful for calculating how much money and/or other assets should be placed into the trust. A financial planner can be of assistance in helping calculate rates of return on different investments and developing an effective financial plan to fund the trust.

## **H. Funding the Trust**

Several different types of assets can be used to fund a trust, including cash and investments such as certificates of deposit or stocks. The trustee has the final authority to decide which investments, if any, he or she will buy with the trust's assets. If a third-party transfers one type of investment into the trust, unless otherwise stipulated, the trustee can decide to change the type of investment. The trustee is the ultimate decision maker regarding trust investments and is expected to make responsible investments.

Parents can purchase life insurance policies to help fund a trust and stipulate that when the insured parent dies, the trust becomes the owner of the life insurance proceeds. Life insurance proceeds can be payable to a living trust already in existence or to a testamentary trust that becomes effective when the parent dies. The amount of coverage and the type of policy chosen depends on several factors, such as the age of the insured and the amount of money needed to provide for the child's needs. Most people do not initially have large sums of money readily available to fund a trust, but trusts can be funded gradually over time. An attorney or tax advisor should be consulted about individual circumstances and potential tax consequences for various funding options.

The following are some examples of ways to fund a trust:

- ✓ Cash, savings and certificates of deposit (CDs)
- ✓ Stocks and bonds
- ✓ Mutual funds
- ✓ Life insurance

- ✓ Pension plans
- ✓ Real estate and personal property

If a trust cannot be fully funded when it is first created, the grantor can gradually fund it over a period of years. The trust can be started with whatever lump sum the grantor is able to contribute, whether a modest amount or a large amount. Subsequent gifts can then be directed to the trust through gifts from the grantor and perhaps other family members or friends. The most effective approach is to make systematic investments, contributing a set amount every month or every other month. One way to ensure that funds are consistently added to the trust is to have an amount automatically transferred from the grantor's bank account.

## **I. Helping with Housing Costs**

A trust can own a home, and money and other assets in the trust can be used for the home's upkeep. This option can offer a long-term living arrangement for the beneficiary of the trust. When adequate supports are properly planned for and provided, people with disabilities can continue living in their own homes.

A home can be transferred into a trust either while the grantor is alive or upon his or her death. A trust can also be created in such a way that the trustee is authorized to use the trust funds to buy a home for the child. If the trust has sufficient assets, the house can be purchased outright. If not, trust funds could be used toward down payment and closing costs and to help pay the mortgage payments. The trust could also loan money to the child for a down payment on a purchase or alternatively, to rent a home if renting would have a less detrimental effect on the child's benefits. Individual circumstances will determine the best option.

SSI considers a person to have an ownership interest in a home held in trust for his or her benefit, because the home is used to provide the person a place to live. Therefore, a home owned by a Special Needs Trust should not be considered a resource to the individual and should not result in a reduction or loss of SSI. However, mortgage payments and property taxes paid by a trust could be counted, and would reduce the child's SSI payments. Other costs like gas and electric and water bills paid by the trust will also result in a reduction of SSI in the months they are paid. In some cases, it could be worth taking the reduction in order to provide the assistance to the child.

Certain housing costs can be or can be paid by a trust without affecting SSI and Medicaid coverage. Examples include: telephone and cable bills, home maintenance and repairs, and

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furniture and appliances within a \$2,000 limit. It might be easier to have the trust pay for these and have the child pay for direct shelter costs, if he or she can afford them. When such costs are paid by the trust, payment must be made directly to the store or vendor. If the money is given directly to your child for any purpose, it will be considered income and will reduce his or her SSI payments dollar for dollar.

Any transfer of real estate to a trust may have significant tax implications for both the grantor and/or the beneficiary. Since SSI policy is not always clear-cut, it is important to have a careful review of any housing plans by an attorney knowledgeable about these issues.

## **J. Choosing a Trustee**

Since the trustee is responsible for administering the trust, it is important to select the trustee very carefully. In addition to a primary trustee, a “successor trustee” should also be named to take over if your trustee is unable, or unwilling, to continue.

The will or trust agreement that creates the trust should include instructions for the trustee as to how and when to give money to the beneficiary. It may give the trustee guidelines but allow him or her to decide how exactly the trust fund will be spent. The trustee has other responsibilities, including managing and investing the trust money, filing tax returns for the trust, and keeping track of how money is spent for the beneficiary.

The trustee must be someone who can administer the trust properly, so as not to jeopardize government benefits. Benefits can be negatively affected even with the best worded trust, if the trustee distributes trust funds incorrectly. A trustee should be capable of managing the amount of money in the trust and should also be familiar with ways to invest money, even though many trustees seek professional investment advice. Even trusts with relatively small amounts may be grown through wise investments. It is helpful if the trustee is familiar with the beneficiary’s needs and preferences. It is also important for the trustee to share the parent’s vision for the child, especially because the trustee will make important decisions after the parent’s death.

State laws, as well as the trust document, require the trustee to spend the trust money for the beneficiary, rather than the trustee’s own benefit. Even though these legal protections are available, the parent must choose the trustee carefully. Some grantors choose a family member or friend to be a trustee, while others name a bank or other financial institution. Financial institutions may only manage trusts over a certain minimum – sometimes as high as \$500,000 – and charge fees for their services based on the amount in the trust or the amount of income the trust generates. Friends or family members serving as trustee may be willing to

do so at little, or no, cost. A trust can be written to financially compensate the trustee for his or her time and service, even if that person is a friend or family member.

#### **IV. Government Financial and Health Care Benefits**

People with developmental disabilities are eligible for public financial assistance and health care benefits to meet basic living needs. These benefits are often essential in meeting a person's daily cost of living. Having a clear understanding of these benefits is vital to assuring that the child receives them, if eligible, and retains them as needed. Federal government programs that provide benefits to people with disabilities can usually be grouped into two main categories: "means-tested" programs and "insurance" programs.

Means-tested benefits are based on need and, therefore, are available only to individuals with disabilities who have very little, or no, money or other assets. Supplemental Security Income and Medicaid are examples of means-tested government benefits. Government insurance programs, such as Social Security Disability Insurance and Medicare, are based on the individual's work record or his or her parents' work record, and are available to all eligible people, regardless of their assets.

##### **A. Supplemental Security Income (SSI)**

Supplemental Security Income (SSI) is a major source of monthly income to people with disabilities. It is a federal entitlement program administered by the Social Security Administration. Entitlement means that everyone who is eligible receives the benefit, and there is no waiting list.

SSI is a cash benefit intended to cover food, clothing and shelter. It is available to people who have disabilities, are elderly, or are blind, and have very little income and assets. Children with disabilities, as well as adults, can receive SSI. Social Security defines disability as a mental or physical condition that keeps the individual from working (for adults) or results in severe functional limitations (for children) and is expected to last at least a year. If a person is under 18, his or her parents' income and assets are usually considered in determining eligibility.

To receive SSI, an individual may not have more than \$2,000 in assets and a couple may not have more than \$3,000. Assets that are considered include cash, bank accounts, stocks and bonds, personal belongings, real estate and any other item of value that a person owns. Social Security, however, does not count everything a person owns in determining eligibility. Things that are not counted include: the home the person lives in, his car up to a certain value, burial plots, and personal and household goods and insurance policies depending on their value. Property is only counted if the beneficiary owns it and has the right to sell it. For example,

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furniture purchased by someone else and used, but not owned, by the beneficiary is not considered an asset. Since there may be other excluded resources depending on the situation, each person's situation must be evaluated individually.

### ***Amount of Benefits***

The amount of SSI a person receives is affected by how much other income he or she has from other sources, including earnings. The maximum monthly SSI benefit in 2014 is \$721 for an individual and \$1082 for a couple.

If an eligible person has no income at all, he or she will receive the maximum amount. A person receives less if he or she has income or receives other types of support for food, clothing or shelter. For example, if adult child with a disability qualifies for SSI and lives at home, the parent is considered to be providing shelter at no cost.

The same would also be true if the parent paid rent for an apartment. The value of this shelter is considered when calculating SSI eligibility.

In some cases, it makes sense to allow SSI to be reduced because the overall result, including the food, clothing and/or shelter being provided at reduced or no cost (called "in-kind support"), is better for the SSI recipient. This is because SSI rules generally do not reduce benefits by the full value of the in-kind support. The amount of the reduction depends on whether the SSI recipient is considered to be living in his own household or the household of another.

When an individual is living with a parent or someone else who owns or rents the home, but he doesn't pay his fair share of shelter and food costs, he or she is considered **living in the household of another**. In this situation, SSI will reduce his or her benefits by one third of the maximum SSI payment (\$238 in 2006), *regardless of the actual value of the support he receives*. This occurs even if the actual value is less than \$238, so it may only be worth providing in-kind support if the support is worth more than the 1/3 reduction.

When an individual is **living in his or her own household**, SSI counts the value of in-kind support up to a "presumed maximum value" (PMV), *regardless of its actual value*. The PMV is one third of the maximum SSI payment plus \$20 (approximately \$258 for an individual in 2014). However, if there is no other income than SSI, the reduction is less. If the beneficiary can prove that the actual value of an in-kind support is less than the PMV, only the actual value will be considered. If the amount of in-kind support counted against a person causes total loss of all of SSI, loss of Medicaid may result. Many people with disabilities rely heavily on Medicaid for health insurance, and may need it more than the SSI cash payments.



The reduction for living in the household of another and the presumed maximum value reduction only apply once per month. Once the reduction is taken, additional in-kind support received that month has no additional effect on SSI.

If the parent is helping to pay food, shelter or clothing costs that are considered in-kind support, it is generally better to pay a greater amount in a single month whenever possible, rather than smaller amounts in numerous months. It is also best to pay as many bills in the same month as possible. The reason is that the presumed maximum value reduction to SSI applies each month in which the SSI recipient receives in-kind support. For example, if a parent or a trust pays the child's water bill in October and the heating bill in November, the child's SSI will be reduced in both months. However, if both bills are paid in November and no bills are paid in October, a reduction will only be taken for one month.

A lump-sum payment a parent or a trust makes for an ongoing cost generally will be averaged over the months to which it applies, if it is for future expenses (e.g., future rent). It will affect the SSI recipient's benefits in each of those months. A lump-sum payment for a past expense that has accumulated over months will generally only count in the month the bill is paid. In comparison, an SSI recipient can prepay expenses with his or her own funds without a reduction in benefits.

### ***What Support Affects SSI Benefits?***

The Social Security Administration considers the following things shelter costs, and therefore, subject to the above rules if provided as in-kind support: rent, mortgage payments, property taxes, property insurance if required by the lender, heating, gas and electric, water, sewerage, and garbage collection.

Expenses that a parent or a trust can provide or pay for without affecting the child's SSI and Medicaid include:

- ✓ Medical and supportive services, supplies, and equipment
- ✓ Vocational and other training
- ✓ Phone and cable and insurance bills
- ✓ Other services such as haircuts, housekeeper, lawyer, home maintenance (e.g., plumber, electrician, appliance repair, painter)
- ✓ Loans not retained into the following month
- ✓ Airline and other transportation tickets (domestic travel)
- ✓ Items that SSI excludes from asset consideration such as a car, furniture and other household goods up to a certain value
- ✓ In-kind food, shelter and clothing once the amount for living in the household of another or the presumed maximum value has been deducted from the SSI payment

## **B. Medicaid (also known as Medical Assistance)**

Medicaid covers the medical expenses of people with disabilities who have very low income and assets. Medicaid is a very complex program, with very strict rules determining who is eligible and what services are covered. In some states, SSI recipients are automatically covered by Medicaid. This link is possible because SSI has the same income and asset tests as Medicaid. If a person does not receive SSI, there are other ways to become eligible for Medicaid.

Some individuals who have disabilities have high medical bills, and sometimes those bills are as much or more than their income. If a person has low or moderate income (though not low enough to qualify for SSI) and high medical bills, Medicaid will keep track of what the person has paid for those bills and when he or she reaches a certain level, Medicaid will cover the remaining bills.

## **C. Social Security Disability Insurance**

The Social Security Administration also oversees Social Security Disability Insurance (SSDI), which is a cash benefit paid to individuals with disabilities and their parents who have worked enough to be covered by the system. Adults with developmental disabilities who have not paid enough into the Social Security system may receive *dependents'* benefits under a parent's work record if the parent worked enough to be covered and has a disability or is retired. Or, a person may qualify under a parent's work record if the parent has died, under the *survivors'* benefits program. In order to receive dependents' or survivors' benefits, the person's disability must have begun before he or she was 22 years old and be expected to last for at least a year.

The size of SSDI benefits depends on how much the person, or his or her parent, earned while working. If a person receives SSDI based on his or her own work record, SSDI determines the amount received based on that work record. If a person receives dependents' or survivors' benefits, the amount is usually a percentage of the covered parent's disability or retirement amount.

The amount of assets a person owns does not affect his or her SSDI benefit. However, income may affect SSDI benefits, depending on whether the income is earned or unearned. *Unearned* income, such as a pension or annuity, is not considered in determining SSDI eligibility. *Earned* income is treated differently because if a person can work and earn a significant amount of income – more than \$800 per month in 2003 – he or she will not meet the disability test and will not be eligible for SSDI benefits. Work incentives exist that can, in certain circumstances,

help people retain eligibility for SSDI if they make more than \$800). Earned income that is less than \$800 per month does not affect SSDI benefits.

If a person receiving SSI begins receiving SSDI, he or she could lose SSI benefits. This situation would occur if the SSDI benefit is \$20 or more than the SSI amount (if there is no other income). Financially, this should not be an issue since the income from benefits would not decrease — just the source. Of concern would be the loss of Medicaid. However, a person who receives SSDI based on the parent's work record rather than his or her own, will retain Medicaid benefits, even if the SSI payments stop.

#### **D. Medicare**

Medicare is the federal health insurance program for individuals receiving Social Security Disability Insurance or Social Security Retirement benefits. A person automatically receives Medicare after getting SSDI for two years, whether qualifying on his own or through a parent's work record. In addition, everyone 65 and older who receives Social Security Retirement benefits is eligible for Medicare.

Medicare Part A covers hospitalizations and related services, while Medicare Part B covers outpatient treatment and physician services. Part B requires eligible recipients to pay a premium, but Part A does not. In addition to the premiums that must be paid on a monthly basis, recipients typically have a co-pay for a portion of their care because Medicare may only pay 80 percent or may start paying only after a recipient has paid a deductible. In some cases, Medicare pays 100 percent or has different deductibles. Medicare Part D covers prescription drugs and medications for people who receive Medicare.

Because Medicare does not cover the entire cost of recipients' care, people may purchase private insurance to pay the co-payments and deductibles. This type of insurance is referred to as "supplemental," "secondary" or "Medi-gap" insurance and only covers the portion Medicare does not cover.

Government financial and health care programs can be very beneficial to people with disabilities, but the conditions and rules can be somewhat complicated. A person may be eligible for any one, or all, of these benefits at the same time.

#### **V. Decision Making**

Minor children and some adults with disabilities need other people to make personal, financial, and/or health care decisions on their behalf, either informally or formally. All adults are legally entitled to make their own decisions, but some adults may need help making some or all decisions. Ideally, even adults with developmental disabilities should be responsible for as many life decisions as possible, relying on others only for those decisions too big or complex for them to handle alone.

### **A. Making Decisions for Others through Guardianship**

Parents have legal authority to make decisions for their minor children (under 18 years old). They are the “natural guardians” of their minor children and have this authority without a court order or any other special documentation. Adults are presumed to be competent to make their own decisions as to their personal well-being and their money unless a court determines that they are not competent. When individuals with disabilities cannot make decisions for themselves, others might help by informally making decisions for them. In some families, the parent’s or other family member’s authority is delegated through a formal process, such as a trust or power of attorney. In this case, the person who receives that authority becomes the guardian of the person with a disability.

Families, along with their attorneys, should consider all informal and formal options before considering guardianship. Legal restrictions on the decision-making ability of a person with a disability must use the “least restrictive alternative.” If none of the less-restrictive decision-making alternatives is possible, the family may pursue guardianship, which involves going to court and having a judge decide whether to give some or most of a person’s decision-making rights to someone else, who is then accountable to the judge. Guardianship is the most restrictive way to assist a person with decision-making. A “guardian of the person” can generally make personal decisions such as where a person will live, what kinds of health care he or she will receive and where he or she will go to school or work. A “guardian of the property” determines how a person’s money is invested and spent. An individual may need a guardian of the person but not a guardian of property, or vice versa.

If a minor child’s parents die, a guardian will be needed to make personal decisions like where the child will live and go to school. This is always true for minor children, regardless of whether the child has a disability. If the parents’ will name someone to act as guardian of the person, that person can serve as guardian without having to go to court. The court will appoint someone to serve as guardian of the person if the parents did not name a guardian in their will.

If a child has money that should be managed and spent for his or her benefit, the court will appoint a guardian of property. This may be the same individual as the guardian of the person. If the child is at least 14 years old, he or she may tell the court who he or she wants as

guardian. The guardianship of the minor will end when the child turns 18, just as if the parents were still alive.

Parents who have minor children should name a family member or friend in their wills to serve as guardian in the event they die before the child reaches adulthood. Because guardianship is a big responsibility, it is a good idea to discuss what it would involve and make sure that the person chosen is willing to take on the responsibility. A parent should consider the person's relationship with the child and his or her other responsibilities or commitments. The proposed guardian may change his or her mind or be unable to assume the responsibility as planned, so it is a good idea to name an alternate guardian, as well.

Guardianship can be broad enough to cover all decisions or may be limited to certain kinds of decisions. It is vital to a person's independence to obtain guardianship only if necessary and to limit the guardianship to the decisions needed. For example, a limited guardianship may give a guardian authority to make medical decisions or to make financial decisions pertaining to a person's home while the individual continues to make other decisions.

A person does not need a guardian simply because he or she has a disability or makes mistakes or choices that others may think are unwise. If someone seeks guardianship of an adult with a disability, he or she must prove to a judge that the person cannot make responsible decisions concerning issues like food, clothing, shelter, or health care or decisions related to money or property because of a disability, and that no less restrictive method is possible.

Although guardianship is available to enable others to make decisions on behalf of people with disabilities, it should be used only as a last resort, after considering all of the options. Some of the options are outlined below.

### ***Guardianship of the Person***

A court will appoint a guardian of the person for an adult if the adult has a disability that makes him or her unable to make responsible personal decisions. Examples of personal decisions include decisions relating to safety, shelter or health care. When a court appoints a guardian of the person for an adult, he or she becomes known as the "ward." The appointment of a guardian of the person does not take away an individual's civil rights.

Sometimes, family members or friends seek guardianship so they can make health care decisions on behalf of a person with a disability. In most cases in which there is no advance directive, a health care surrogate should be able to make all medical decisions, including decisions about life-sustaining treatment, without having to become a court-appointed guardian. If a health care decision must be made and it cannot be made any other way, guardianship may be the only option. Individuals and families may need the services of an attorney who is familiar with the state health care legislation governing advance directives and

surrogate decision making, as well as guardianship, in order to make an informed choice of options.

In some states, including Maryland, the true guardian of the person is the court. The court appoints the guardian and delegates him or her authority to act on behalf of the individual, yet requires the guardian to obtain permission before making certain decisions. For example, the guardian must get court approval to take such steps as changing the person's type of residence or authorizing psychotropic medications. If a medical procedure involves a "substantial risk to life," the guardian must ask the court for special permission related to the procedure. This is true whether the guardian wants the individual to have the procedure or wants to withhold the procedure. In some situations, if a close family member is the guardian, the court will give that person the authority to make all decisions related to life-sustaining procedures when the guardianship is established. Otherwise, the guardian must make a special request to the court. A person under guardianship may still make certain day-to-day decisions, such as what to wear and who to have as friends.

### ***Guardianship of the Property or Conservatorship***

A guardian of the property (or in Virginia and D.C. conservatorship) is necessary if decisions need to be made related to a person's property or money, but that person cannot make those decisions due to a mental disability. A guardian of property can only make decisions about an individual's property and money, such as selling property, paying bills, or buying things. As in guardianship of the person, the court is the ultimate guardian and delegates only certain powers to the guardian of the property. The guardian must give the court an annual accounting of how he or she spent the individual's money.

Once a guardian of property is appointed, the guardian may spend the individual's funds for his or her daily support or care. The guardian may also spend the ward's funds to support people legally dependent on the ward, such as a minor child or spouse. If the guardian wants to spend the individual's money for anyone else or make gifts from the individual's money, the guardian must make a request to the court.

### ***How to Become a Guardian***

When guardianship is the last and least restrictive option, and someone wants to become guardian for a person with a disability, he or she must submit a document called a "petition" to the court. The person seeking guardianship is known as the "petitioner." Usually, the petitioner is represented by an attorney who prepares the legal documentation. The petition must state why the petitioner is seeking guardianship, the relationship between the petitioner and the

person with a disability, and what kinds of decisions the petitioner wants to make. The petition must also include written statements describing the person's disability.

When the court receives the petition, it appoints another attorney to represent the person with a disability. The attorney usually meets with the person, reviews all available records, talks with people involved in his or her life, and determines whether the person has the ability to make personal and/or financial decisions. The attorney should also ask the person how he or she feels about the guardianship and the proposed guardian.

The petitioner and both attorneys must attend a hearing in court. The person with a disability may attend if he or she chooses to do so. The petitioner must prove that the person is "disabled" within the meaning of the law, that the person needs a guardian, and that the petitioner is the best person to be the guardian. The judge then determines whether a guardianship is necessary, who should be appointed as guardian, and rules on other requests in the petition.

Unless there is a life-threatening emergency, guardianship may take up to several months to be established. The process is time-consuming because the petitioner must gather information to prepare the petition, interview the appropriate people and schedule the hearing. The process can also be expensive, because the attorneys representing the petitioner and the person with a disability must be paid and there are court costs for filing a petition.

The guardian must keep records of all actions taken in his or her role as guardian. After the guardianship is established, annual reports must be filed documenting a guardian of the person's decisions and how a guardian of the property has spent the individual's funds. If court permission is required to make a certain decision, the guardian must request authorization from the court and should not act until the court has issued an order authorizing the action. Sometimes, guardians rely on attorneys to help them with these reports and motions.

## **B. Advance Directives**

A "health care agent" can make health care decisions on behalf of another person. A person names his or her own health care agent in an "advance directive." Advance directives can also be used to communicate one's wishes regarding medical treatment and other health care issues. Advance directives may include instructions to the agent regarding whether to provide, withhold or withdraw certain medical treatments, often referred to as life-sustaining treatment. Examples include artificial nutrition and hydration (tube feeding) and mechanical ventilation.

An advance directive may also be called a “health care power of attorney,” “medical power of attorney,” or “living will.” Advance directives are usually written, but may be made orally, and both written and oral advance directives must be witnessed. The person signing the advance directive must be over age 18, competent to make an advance directive, and able to communicate his or her health care wishes. A competent individual is one who is capable of deciding about the issue presented, which means that he or she can understand the nature or the result of the treatment, is able to evaluate the risks and benefits of the treatment, and is able to communicate a decision related to the treatment.

Advance directives can be written with the assistance of an attorney or made by completing forms available online. An attorney can draft an advance directive that is more detailed or individualized than those provided online. An advance directive can be written to become effective as soon as it is signed or only after the individual becomes unable to make his or her own health care decisions.

### **C. Surrogate Decision Making**

If an individual is not competent to execute an advance directive and did not sign one in the past, a surrogate can make health care decisions on that person’s behalf. State laws stipulate who may act as surrogates. In order for a surrogate to be able to make health care decisions, two physicians must sign a certification stating that the individual is unable to make informed decisions. A surrogate must make decisions based on the wishes of the individual, if they are known. If the wishes are not known, the surrogate must consider issues like the individual’s diagnosis, his or her wishes regarding life-sustaining treatment, and religious or moral beliefs.

In some states, including Maryland, the following individuals or groups, in the priority order listed, may make decisions without going to court about health care for a person who has been certified to be incapable of making an informed decision and who has not appointed a health care agent.

A person may make a decision only if all higher priority individuals are unavailable or unwilling to assume that role:

1. A guardian, if one has been appointed
2. A spouse
3. An adult child of the patient
4. A parent
5. An adult brother or sister of the patient



6. A friend or relative, who must demonstrate that he or she has maintained contact sufficient to be familiar with the patient's activities, health and personal beliefs

#### **D. Advocates**

Often, family members and friends of people with disabilities step into the role of "advocate," sometimes without even realizing they are doing so. This role is typically very informal, since it requires no documents or court hearings. In spite of the informality of the advocacy role, an advocate can have a tremendous impact on an individual with a disability and his or her quality of life. Many people with disabilities may choose the people they want to advocate on their behalf.

An advocate may participate in planning meetings, help a person choose, acquire and monitor supports and services and help a person make life decisions. To be most effective, the advocate should become familiar with the resources available in the community and eligibility criteria for benefits, as well as the needs and preferences of the person with a disability.

#### **E. Durable Power of Attorney**

A competent adult can execute a durable power of attorney (DPOA), which appoints someone to act on his or her behalf to make legal and financial decisions. The DPOA must be in writing and must be witnessed and notarized. The DPOA can be broad or it can be limited so that the agent can only make certain types of decisions, such as write checks from a checking account or sell the individual's home.

A power of attorney is "durable" if it remains effective after the individual becomes incapable of making his or her own financial and legal decisions. The DPOA can be written to become effective as soon as it is signed or only after the individual becomes unable to make his or her own financial decisions.

#### **F. Trusts**

A parent, family member, or other person can establish a trust with money or assets to benefit an individual with a disability. A "trustee" is named to manage some or all of the assets. The trustee has full authority to make all decisions regarding assets in the trust, including how to invest and spend the trust money.

Trusts can vary widely, so that they can be worded to meet your intent and the beneficiary's needs. While they provide a management tool that can eliminate the need for guardianship of the property, they have other uses as well. In particular, they are a mechanism that allows someone to leave money and assets to another person without jeopardizing vital public financial and health care benefits, as discussed in a previous section.

### **G. Representative Payee**

If a person who receives financial benefits from the federal government, such as SSI or SSDI, needs help with depositing the checks, paying bills, and managing money, the government may appoint someone to act as "representative payee." A representative payee must complete some forms and have a doctor establish that the person with a disability is unable to manage his or her assets. The government will then issue the checks in the name of the representative payee and will require that the representative payee open an account into which the checks are deposited. The representative payee must spend the money only for the benefit of the person with a disability and keep accurate records of how the government benefits are spent.

### **H. Informal Options**

Joint accounts offer an informal means of assisting a person with a disability in managing his or her money. If a person with a disability owns a joint bank account with another person, either owner may access the account. For example, if a father and his son with a disability are co-owners of the son's account, the father can deposit checks, pay bills and make other decisions related to that account. Unfortunately, joint accounts involve some drawbacks, including the fact that the joint owner is not required to account for how the money is spent. With a joint account, there is nothing to assure that the money is used for the benefit of the individual with a disability. Another limitation is that even though a joint owner can make financial decisions for a person with a disability, the person with a disability can make withdrawals even if he or she makes poor judgments in spending the money. Also, the joint account is counted in determining government benefit eligibility for the person with a disability.

Another type of informal arrangement is one in which a family member holds money for a person with a disability. The money may have come from a parent or from the individual with a disability. There may be some moral obligation to use the money for the individual, but there is no way to make sure the holder of the funds spends the money as intended.

Even if the family member has the best intentions, the heirs or creditors of the person holding the money may claim it. This would deprive the person with a disability of his or her money with no way of getting it back.

## VI. Other Planning Considerations

There are several other important issues to consider when planning how to leave money or other assets to your family. These include minimizing the impact of taxes, planning for potential long-term care needs you may have, and working effectively with professionals.

Estate planning must be comprehensive and consider the context of the person's life, his or her goals, and the roles and responsibilities as an individual, spouse, parent, and/or other family member. Special Needs Trusts, decision-making and benefits for a family member with a disability are of primary concern in estate planning. Planning issues will vary depending on many factors, including the person's age, health status, marital status, assets, the number of dependents and any special needs they may have and the person's own long-term care needs.

### A. Tax Issues

There are several different taxes imposed by federal and state governments, including *gift and estate taxes, inheritance taxes, income taxes, and capital gains taxes*. These taxes may apply whether one is planning for a person with a disability or not. Since tax laws change significantly from one year to the next, it is important to obtain the assistance of an attorney, accountant and/or financial planner to analyze your situation to determine whether taxes can be reduced or avoided.

#### ***Gift and Estate Taxes***

Federal gift and estate taxes get a lot of attention because the tax rates are high, up to 55 percent in some estates. For this reason, many individuals and couples seek ways to reduce or avoid gift and estate taxes. Federal law allows each person to transfer up to \$5 million in assets to other people without having to pay federal gift or estate taxes.

This can be done through lifetime gifts and transfers occurring at death and is known as the "applicable exclusion amount." Maryland still has an estate tax exemption of \$1 million.

The federal applicable exclusion amount may be used a little at a time and applied to gift and/or estate taxes. If a person's assets total \$1 million or more, or will in the future, some estate planning options may be available to avoid or reduce gift and estate taxes. People with significant you should consult an attorney or financial planner.

Some other points to consider regarding gift and estate taxes include:

- A person can avoid gift taxes through the “annual exclusion.” This option allows a person to give away a limited amount to any number of individuals and couples every year, without using any part of your applicable exclusion amount or paying federal gift taxes. The limit is a gift of \$14,000 per individual and \$28,000 per married couple, each year.
- Irrevocable life insurance trusts can own insurance on a person and when the person dies, the insurance proceeds are not considered part of his or her estate.
- Married couples have increased options available because federal gift and estate tax does not apply to gifts or estate transfers to spouses. Also, married couples can have wills that create trusts to make sure each spouse can use the applicable exclusion amount to transfer assets tax-free.

### ***Inheritance Tax***

State inheritance tax is assessed upon death regardless of how much is in an estate. It applies to all probate assets and most non-probate assets. The tax rate varies from state to state. In Maryland, there is no tax for estate assets passing to spouses, parents, children, grandchildren, great grandchildren, etc. and ten percent to anyone else, except charities. Some special exemptions apply to assets passing to spouses. Inheritance tax on probate assets and some non-probate assets must be paid before an estate can be closed.

### ***Income Tax and Capital Gains Tax***

Income tax considerations are important for trusts as well. The assets transferred into a trust are not taxed but the income the trust earns will be taxed. Once created, some trusts must obtain a tax identification number and file tax returns.

Capital gains taxes must be considered when giving away certain property during a person’s lifetime, such as real estate and stocks. If the property value has increased since it was purchased, the increase is a capital gain and will be subject to capital gains taxes when the property is sold.

Tax issues are extremely complicated and should be approached only with the assistance of an accountant or attorney who has tax experience or other tax advisor. Additionally, he or she should know about special provisions that may be available to people with disabilities or high medical expenses.

## **B. Long-Term Care Needs**

To avoid depleting savings that a person may want to leave to his or her children, it is important to consider the long-term care needs for later in life. People receive long-term care in their own homes, assisted living facilities and in nursing homes. No matter where the care is provided, it is usually very expensive. We all hope we will never need long-term care. Unfortunately, it is becoming more likely as people are living longer and fewer family members seem to be available to care for elderly relatives.

One way to plan for long-term care is to buy long-term care insurance. There are many types of long-term care insurance policies and the decisions can be very confusing. It is important to work with an insurance broker who is well-informed about long-term care insurance in general and the insurance companies and policies that are available to you. Like most insurance, long-term care insurance becomes more expensive as a person get older. People who already have certain illnesses may have to pay very high premiums or may not be able to qualify for a policy. Also, people with modest incomes and/or other expenses may not be able to afford any additional premium. For these reasons, long-term care insurance is not the answer for everyone.

Some individuals can pay for their long-term care through their savings or income, or a combination of the two. Because long-term care is so expensive, many individuals and couples must rely on Medicaid to cover some or all of the cost. Medicaid covers long-term care in nursing homes and has special rules to protect the spouse who continues to live at home. Medicaid also allows people to transfer certain assets to individuals with disabilities (or to trusts for individuals with disabilities) without jeopardizing the Medicaid long-term care eligibility of the person transferring the assets. Because Medicaid law is so complex and changes frequently, each case must be evaluated considering the current law and facts of the situation. To learn about special protections and to prevent disqualification from Medicaid, it is important to consult an attorney who is familiar with Medicaid's rules for long-term care.

## **In Conclusion**

Estate planning may seem a daunting task. While there is a level of complexity, this crucial plan can be successfully completed in collaboration with a trusted attorney. On the part of the family, estate planning requires some forethought, organization, careful consideration, and decision making to see the plan to fruition. Parents with a child that has a disability do have special considerations as they look to the future. An attorney with expertise in disability law and special education trusts can work collaboratively with the family to develop a thoughtful plan that is individualized for their unique circumstances. There is a confidence and peace of mind that can be found when the proper documents and plans are in place, ensuring that a child will be well provided for and protected in the years ahead.