

# Planning for family members with special needs

Proper financial planning can enable a comfortable lifestyle for loved ones without compromising their eligibility for government benefits.

In today's world, pursuing your life's goals is being challenged in new ways. Which makes now the perfect time to review your goals in terms of "Advice. Beyond investing." Because when we collaborate on what matters most to you, we can create a plan tailored for you.

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Countable income first reduces the benefits available and then—once the amount is large enough—blocks eligibility for benefits entirely.

While financial planning and estate planning are challenging exercises in the best of circumstances, the complexity of designing an effective plan increases significantly for families where one or more members have special needs. Typical planning goals, such as paying for college or distributing wealth equally among children, must be reconsidered. A family seeking to qualify for public benefits encounters additional government regulations that influence providing support for and transferring assets to family members with special needs.

#### **What are “special needs?”**

“Special needs” is a term that can apply to various learning disabilities, medical or behavioral issues. An individual may be born with a disability or become disabled later in life due to an illness, medical complications or debilitating injury or accident. The designation is often used to ascertain an individual’s eligibility for special services, programs and government benefits. Some individuals with special needs may qualify for government assistance—such as the Social Security Administration’s Supplemental Security Income (SSI) program or Medicaid health services—while others may not.

#### **Public benefit eligibility**

Public benefits are available to disabled individuals. The federal government considers a child to be disabled for purposes of SSI benefits when the child has a medically determinable physical or mental impairment (including an emotional or learning problem) that results in marked and severe functional limitations that is expected to be long-lasting or fatal.<sup>1</sup> In order to qualify for certain government benefits, household income may not exceed a certain threshold, which is based in part on the number of other children in the household, the number of parents in the household and whether the household income is earned or unearned.<sup>2</sup>

The federal government considers an adult to be disabled when the adult has a medically determinable physical or mental impairment that makes him or her unable to engage in any “substantially gainful activity” and that is expected to be long-lasting or fatal.<sup>3</sup> In addition, to qualify for certain benefits, adults must meet income and asset tests.

The income limit test for adults can be very complex, depending on the mix of earned income, unearned income, in-kind income and deemed income. Most income is countable with some exceptions (e.g., \$20/month of income is not countable, and different limits apply to earned versus unearned income). Countable income first reduces the benefits available and then blocks eligibility for benefits entirely once the amount is large enough.<sup>4</sup>

The asset (or “resources”) test is more straightforward. An individual seeking SSI or Medicaid cannot own assets in excess of \$2,000 (\$3,000 for a married couple).<sup>5</sup> Certain assets such as a home, household possessions and a car are excluded from the definition of assets.<sup>6</sup> A well-intentioned birthday gift from a family member that exceeds the \$2,000 threshold will result in the loss of government benefits to the recipient. Those who enroll and later lose eligibility may face tough legal battles to regain access.

A Special Needs Trust is specifically structured such that the trust assets are not deemed to be assets of the disabled beneficiary but may be distributed for his or her benefit.

### **Public benefits**

Children under the age of 18 who meet all of the tests described above can apply for Supplemental Security Income (SSI) benefits, special education resources and locally based resources. Adults can also receive SSI benefits, even if they continue to live at home. The maximum 2019 SSI benefit is \$771 per month for an individual and \$1,157 per month for a couple.<sup>7</sup> Keep in mind that those amounts are reduced by countable income. All states supplement SSI benefits in a variety of ways except for Arizona, Mississippi, North Dakota and West Virginia.<sup>8</sup> In addition, most states make Medicaid available to individuals who qualify for SSI benefits.<sup>9</sup>

### **Planning to preserve public benefits**

#### **The Special Needs Trust**

The Omnibus Budget Reconciliation Act of 1993 explicitly authorized the use of a Special Needs Trust (SNT) to address the goal of some families to provide additional resources for their disabled family members without disqualifying them for government benefits.<sup>10</sup> An SNT is specifically structured such that the trust assets are not deemed to be assets of the disabled beneficiary but allow for distributions to be made for his or her benefit. The SNT is meant to provide for the extra needs that are not covered by government benefits. It should specify that the trust is intended to provide “supplemental and extra care” beyond that which the government provides and not intended as a basic support trust. An SNT can provide for the disabled person’s comfort and happiness including necessary or desirable equipment (e.g., a specially equipped vehicle), training and education, insurance, transportation, essential dietary needs, spending money, electronic equipment, computers, vacations, entertainment, payments for a companion and other types of quality of life enhancements. It has the ability to hold everything from cash and investments to real property. There are three types of SNTs:

#### *1. Self-funded trust*

The self-funded Special Needs Trust is a trust funded with the disabled individual’s own assets.<sup>11</sup> These may be assets that were gifted, inherited or awarded as damages awarded from a lawsuit. A disabled person can fund the trust with his or her own assets (or a court appointed guardian may do it on his or her behalf) and still be eligible for Medicaid benefits and SSI. However, upon the disabled person’s death, the self-funded SNT is subject to a “payback provision,” which requires any remaining trust assets to pay back the state agency which administered the Medical Assistance Program. In essence, the state has a lien on the trust. When the trust beneficiary dies, Medicaid is repaid. Congress views this payback provision as a fair trade-off of allowing the disabled person to fund an SNT with his or her own assets.

In December 2016, President Obama signed a new provision into law that allows a disabled person to create a self-funded SNT.<sup>12</sup> Prior to enactment of the law, only the individual’s parent, grandparent, guardian, or a court could create such a trust despite the fact that the disabled person’s own assets would be used to fund the trust.

#### *2. Third-party funded trust*

An SNT can also be created and funded by a third-party—like a family member—for the disabled individual.<sup>13</sup> Again, the assets in this trust will not be regarded as owned by the disabled person, thus allowing him or her to continue to qualify for government benefits. These trusts are the ideal receptacle for gifts and/or inheritances from parents, other family members and friends who want to benefit the disabled individual. The SNT can even be

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named as the beneficiary under a will or revocable trust, or of life insurance and retirement benefits. Laws regarding the third-party funded SNT may vary from state to state. It is important to consult with legal counsel to determine the appropriate type of trust to create.

### *3. Pooled trust*

Another type of SNT is the pooled trust.<sup>14</sup> The trustee of a Pooled Trust is a non-profit organization that manages the collective funds of many disabled individuals but maintains separate accounts for each individual beneficiary. At the death of an individual beneficiary, his or her remaining trust account can either be used to repay the state agency or remain in the trust to be used by other disabled beneficiaries (though a specific beneficiary cannot be named under a pooled trust). Pooled trusts are typically used when a corporate fiduciary is desired but the disabled person's assets (whether their own or a potential gift from a third-party) are relatively modest in size.

### **Structured settlements**

Structured settlements are typically received as a result of a personal injury or medical malpractice lawsuit and often provide periodic payments over time in lieu of a lump-sum settlement. If the insurance company or payor makes the payment directly to the special needs individual, such payments will count against the qualification limits unless the funds are contributed to a self-funded trust. Alternatively, if a third-party funded trust is established, the settlement can be directed to pay to the trust rather than to the individual. In most states, any funds remaining in the third-party trust after the disabled person dies could be left to designated beneficiaries (e.g., children, siblings or other family members) rather than be subject to the payback provision of the self-settled trust.

### **Education funding**

A way of investing for future education expenses of children or grandchildren is the use of Section 529 Plans or custodial accounts via the Uniform Gifts to Minors Act (UGMA) or Uniform Transfers to Minors Act (UTMA). However, these investment vehicles may not be appropriate for disabled individuals. Funds in a custodial account become the child's property at the age of majority (18 or 21, depending on the state and the manner in which the account was funded). As such, the custodial account will count towards the \$2,000 asset threshold and could render the disabled young adult ineligible for government benefits. Distributions of gains from a 529 plan must be made for qualified education expenses related to enrollment or attendance at an eligible education institution in order to avoid income tax and penalties. Generally, 529 plan funds must be used for postsecondary schools that are eligible to participate in the U.S. Department of Education's student aid program and in some states under the Tax Cuts and Jobs Act of 2017 529 plans may distribute up to \$10,000 per student per year for tuition at a public, private or religious elementary or secondary school). 529 plans were not necessarily designed with the disabled student in mind; therefore, the specialized educational needs of a disabled student may not be "qualified" education expenses under 529 plan requirements. In many cases, an ABLÉ account as covered by Section 529A of the Internal Revenue Code (see below) may be a better choice than a 529 plan.

### **ABLE accounts**

Congress enacted the Achieving a Better Life Experience Act of 2014 (the ABLÉ Act) in 2014.<sup>15</sup> The disabled person is both the owner and the beneficiary of the ABLÉ account (similar to custodial accounts), which is a state-sponsored

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tax-advantaged account used to pay for qualified disability expenses. The first \$100,000-\$102,000 (depending on the disabled beneficiary's other personal assets) in an ABL account will not affect a person's eligibility for SSI, Medicaid or other public benefits. If the account exceeds \$100,000-\$102,000, then the individual's SSI benefits will be suspended until the account falls back below the required threshold, but Medicaid benefits will not likely be affected. Total ABL account annual contributions from any source cannot exceed \$15,000 in aggregate, unless the ABL account holder works and is qualified to contribute more under the ABL to Work Act. Additionally, the Tax Cuts and Jobs Act of 2017 allows annual rollovers from a 529 plan to an ABL account in amounts up to the gift tax exclusion, which is \$15,000 per person per donee in 2019.<sup>16</sup>

An ABL account can be used to pay for "qualified disability expenses" such as education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services and other expenses which help improve health, independence, and/or quality of life. Recently, UBS has partnered with the ABLEAmerica program at American Funds to offer ABLE accounts for disabled individuals

### **Spouses**

Spouses may become disabled due to accidents or debilitating illnesses, such as Alzheimer's or dementia. In order to qualify for government benefits, the disabled spouse must meet the needs-based tests discussed above. The usual approach to qualifying a disabled spouse is to reduce his or her income and assets below the financial limits by transferring assets to the non-disabled spouse, though this may result in an ineligibility period. And for married couples with children from a previous marriage, this approach can be controversial with the disabled spouse's children, although use of a qualified terminable interest property (QTIP) trust can lock-in how the principal will be distributed when the non-disabled spouse dies. A QTIP trust is an irrevocable trust that allows a donor-spouse to transfer property to a donee-spouse typically without using up any of the donor-spouse's lifetime gift tax exemption due to the marital deduction.

Married couples in community property states face an additional challenge. These states include Arizona, California, Idaho, Louisiana, Nevada, New Mexico, Texas, Washington and Wisconsin. These states regard property acquired during a marriage as community property and both spouses have an equal right to possess the property during their marriage. Removing assets from the disabled spouse's ownership requires that disabled spouse agree to legally give up his or her community property rights in the property.

### **Planning for the death of a primary caregiver**

#### **Successor guardian**

A parent or guardian should identify someone to take his or her place as the primary caregiver of the disabled person in the event he or she becomes unable to fill that role. A guardian for minor children can be nominated in a will or other estate planning documents. That person must then be approved by a court having jurisdiction. For an adult with special needs who is currently under guardianship, a successor guardian can be nominated in a will. In the event no successor guardian is named, a court proceeding will also be necessary to identify an appropriate person to act.

#### **Plan of care**

In addition to naming a successor guardian or caregiver, creating a Plan of

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Care document can help facilitate a smooth transition from one caregiver to another. A Plan of Care is not a legal document. Rather, it is a personal communication from the current caregiver to future caregivers that shares insights about the disabled individual's personal preferences with respect to clothing, housing, educational, recreational and social needs, wants and desires. It can address details as specific as the brand of soap or shampoo he or she prefers. The document should also include contact information for the individual's primary care physician, specialists, therapists and other professionals. This document should be reviewed and updated periodically.

If something happens to the primary caregiver, the next person can step in and seamlessly continue caring for the disabled individual based on specific and detailed instruction and with the goal of making the transition easier for both the individual and the new caregiver.

### **Long-term financial needs**

It is perhaps an understatement to say the cost of care for a disabled person can be staggering. While medical expenses may be covered by Medicaid, there are often other financial expenses, such as physical therapy or special assistance (e.g., assistance with daily living activities such as bathing, dressing or eating) that will not be covered and can be substantial. Parents who wish to leave a bequest to their disabled child should establish an SNT (discussed above) to receive the inheritance for the continued care of their child. This same trust can be used to receive gifts and/or inheritances from other family members or friends.

Another common means of ensuring adequate funding of long-term care requirements is through life insurance. The trustee of the SNT, rather than the disabled individual, should be designated as beneficiary of the life insurance policy to avoid jeopardizing government benefits eligibility.

### **Conclusion**

Proper financial planning can enable a comfortable lifestyle for loved ones without compromising their government benefit eligibility. It can also help to ensure appropriate arrangements for the continued care, companionship and financial support of a disabled family member. Clients may wish to consult with their financial advisors and professionals who specialize in planning for individuals with special needs.

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See important notes and disclosures on the next page

- <sup>1</sup> <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>.
- <sup>2</sup> <https://www.ssa.gov/ssi/text-child-ussi.htm>.
- <sup>3</sup> <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>.
- <sup>4</sup> <https://www.ssa.gov/ssi/text-income-ussi.htm>.
- <sup>5</sup> <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>.
- <sup>6</sup> <https://www.ssa.gov/pubs/FN-05-11015.pdf>.
- <sup>7</sup> <https://www.ssa.gov/oact/cola/SSI.html>, see <https://www.ssa.gov/oact/cola/SSlamts.html> for a table of historical maximum benefits
- <sup>8</sup> <https://www.ssa.gov/ssi/text-benefits-ussi.htm>.
- <sup>9</sup> <https://www.ssa.gov/ssi/text-other-ussi.htm>.
- <sup>10</sup> 42 U.S.C. §1396p (d) (4).
- <sup>11</sup> 42 U.S.C. §1396p (d) (4) (A).
- <sup>12</sup> 21st Century Cures Act, H.R. 34 – 114th Congress (2015-2016).
- <sup>13</sup> 42 U.S.C. §1396p (d) (4) (A).
- <sup>14</sup> 42 U.S.C. §1396p (d) (4) (C).
- <sup>15</sup> <http://www.ablencr.org/about/what-are-able-accounts>. See also the Tax Cuts and Jobs Act of 2017, Full title, "An Act to provide for reconciliation pursuant to titles II and V of the concurrent resolution on the budget for fiscal year 2018." Pub.L. 115-97 (December 22, 2017).
- <sup>16</sup> 42 U.S.C. §529A(b)(2)(B); §5203.

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