



## CHAPTER 12

# SPECIAL CONSIDERATIONS FOR DISABLED DEPENDENT ADULT CHILDREN

### INTRODUCTION

Families with disabled dependents face special considerations. The disability community is the only minority group that anyone can unexpectedly join at any time. In recent years, The Arc of the United States identified the issue of aging family caregivers as an important concern for disabled dependents. Families need to plan carefully for the eventual transition to the next generation of caregivers. This topic is a complex web of long-term services and supports to navigate, further compounded in its difficulty by the impact of dealing with the caregiver's own health care and long-term care needs. Early planning is essential for success and it involves more factors than can be addressed in this brief chapter, such as: housing, public benefits, caregiver choices, guardianship and legal authority, advocacy, trustees and more.

### A. Government Benefits: SSI, SSDI and MassHealth

#### 1. Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is a means-tested benefits program that pays monthly benefits to low-income older adults (ages 65 or older), disabled adults, and disabled or blind children. Disability for adults is defined as the inability to work ("to engage in substantial gainful activity" in Social Security terms) due to medical conditions that are expected to last at least one year or result in death. The program bases financial eligibility on income and assets. In order to be eligible for the benefit, an individual cannot have more than \$2,000 in countable resources.

SSI benefits are funded by the federal government and provide monthly cash assistance. Some states, including Massachusetts, supplement the amount of the SSI stipend with additional funds.

Although the living situation of the SSI recipient initially determines the amount the recipient will receive from SSI, other factors, principally

what other income, earned or unearned, the recipient receives, can reduce the monthly payment. Generally, the more income an individual has, the lower the SSI monthly payment. It is important to note that the SSI rules greatly favor income from work ("earned income"), and the reduction to the SSI benefit from earned income is lower than from other income.

An individual eligible for SSI in most states, including Massachusetts, will be automatically eligible for Medicaid benefits (MassHealth in Massachusetts) not including nursing home Medicaid and certain MassHealth Home- and Community-Based Waiver Services.

If an individual receiving SSI or Medicaid benefits inherits a large sum of money directly rather than in a properly drafted trust, then that person may be disqualified from the program.

#### 2. Social Security Disability Insurance (SSDI)

Social Security Disability Insurance (SSDI) is an earned benefit available to individuals over the age of 18 who are unable to work because of a medical condition that is expected to last at least one year or result in death. This definition is the same disability standard as in the SSI program described on this page. The benefit is based on the person's work record and how much they have contributed to Social Security rather than on assets or income. SSDI benefits are administered by the Social Security Administration, and the program is largely funded by a participant's payments into Social Security during their working years. Since SSDI benefits are based on an individual's work record and not on their assets, an inheritance will not disqualify a recipient from receiving benefits.

SSDI also provides cash benefits for eligible family members. For example, a disabled adult child may also be eligible for SSDI on a parent's record if the disability began before the age of 22 and has been continuous, and if the parent is

drawing their own Social Security benefits, or is deceased, and paid into the Social Security system. These benefits are sometimes referred to as Disabled Adult Child (DAC) benefits. A child may also start receiving a monthly private pension or other income upon a parent's death.

One of the consequences of SSDI or other non-working income, however, may be the loss of MassHealth benefits or the need to pay a premium for those benefits. (Note that income for public benefits programs differs from taxable income, and what is considered income varies from program to program. Additionally, income limits for MassHealth Standard are lower than the income limits for MassHealth Home- and Community-Based Waiver Services.) If a disabled adult child receives a higher SSDI payment than the monthly SSI payment, then the adult child will be ineligible for SSI payments and may lose their automatic eligibility for MassHealth.

This loss of SSI may require a separate MassHealth application and special planning for continued MassHealth eligibility. Many times, this problem can be fixed by seeking a court order to assign pension payments or other income to a d4A trust (discussed on this page); however, some pensions and Social Security payments are non-assignable. Fortunately, there is a MassHealth regulation in place that protects individuals whose DAC benefits cause them to be over the income limits for MassHealth Standard. An older adult with a dependent adult child who receives SSI benefits must be mindful of the eligibility requirements and should

### **3. Differences Between SSI and SSDI**

There are many significant differences between the SSI and SSDI programs. Among them are: a) how work income is treated, b) how distributions from trusts are treated, and c) the impact of supported housing. These differences go beyond the scope of this chapter. Suffice it to say that one needs to have a thorough knowledge of these programs and their differences.

## **B. Special Needs Trusts**

A special needs trust (or supplemental needs trust) is a planning technique an attorney can utilize as part of an estate plan to offer a family flex-

ibility and control over assets as well as protection for the dependent child's government benefits. The assets held in a properly drafted special needs trust are for the dependent child and are generally used to supplement the dependent child's needs that are not paid for with government benefits. A trustee uses their discretion to manage and distribute assets on behalf of the child.

### **1. Types of Special Needs Trusts**

There are two basic types of special needs trusts: third-party settled trusts and first-party self-settled trusts.

Third-party settled trusts are created and funded by a third party. For example, a parent or other individual can establish a special needs trust and direct assets to the trust established for the benefit of a dependent child. The assets did not originate from the beneficiary. These types of trusts can be established at death by an individual's will (testamentary trusts) or during an individual's life by a separate trust. The provisions of the special needs trusts can include the ultimate disposition of the assets once the beneficiary child passes away (e.g., the remaining assets can go to other family members).

First-party or self-settled trusts hold the assets of the beneficiary. If properly established, the assets in a self-settled trust do not disqualify the beneficiary from SSI or Medicaid benefits. For example, if the beneficiary is injured and receives a settlement or award, those proceeds can be deposited into the special needs trust and not be considered a countable resource. In order to be properly established, this special needs trust must: 1) be established by the disabled individual, a parent, grandparent, legal guardian or the court; 2) be funded prior to the disabled beneficiary attaining age 65; and 3) provide a payback provision that states the Commonwealth of Massachusetts and other states will receive payment to the extent the beneficiary received Medicaid benefits during the beneficiary's entire lifetime (not just since the funding of the trust) upon the beneficiary's death. These types of trusts are usually referred to as "d4A trusts" in reference to their statutory title.

In addition to d4A trusts, d4C trusts are another type of self-settled trust. d4C trusts are pooled trusts that have all the same requirements

as d4A trusts, but differ in that they are administered by a nonprofit organization and not an individual trustee. Having a nonprofit administer the d4C trust makes it possible for the pooled trust to take smaller trust deposits while being economical with fees. It also allows for individuals who cannot identify an appropriate trustee to manage their funds. Currently, pooled trusts are available to persons of any age. However, MassHealth proposed regulations in 2016 that would penalize funding these trusts for individuals over age 64. These regulations are still pending. Therefore, individuals should consult with knowledgeable elder law attorneys before considering this option.

These trusts must be reported to both Social Security and MassHealth when created or upon application for certain benefits by the disabled individual. (Note that Social Security recently stopped requiring reporting of unfunded third-party trusts.) Both agencies will review how the trusts were established, the trusts' terms, and how the trusts are administered to determine whether the trust assets are countable or whether a transfer penalty period will apply.

## **2. Special Needs Trusts and Long-Term Care Planning**

Special needs trusts can also be used during the legal spend-down process for an individual to qualify for long-term MassHealth benefits. The transfer of assets to a special needs trust established for the sole benefit of a totally and permanently disabled person under the age of 65 is not a disqualifying transfer for an older adult seeking MassHealth long-term care benefits. Under the terms of the trust, the trustee must use the funds in a manner that is actuarially sound based upon the beneficiary's life expectancy, or the trust must contain the same pay-back provision as a self-settled trust (as discussed in Section 1).

## **3. Third-Party Special Needs Trusts as Beneficiaries of Retirement Plans**

When individuals attain a certain age, they are required to withdraw mandatory required minimum distributions (RMDs) from their retirement accounts. Individuals may designate certain beneficiaries to inherit the balance of their accounts after their death. The SECURE Act, signed into

law on Dec. 20, 2019, created a number of changes for retirees (e.g., delaying the age to begin to take RMDs from 70.5 years to 72) and beneficiaries (e.g., limiting the amount of time over which a beneficiary may withdraw from the inherited account).

The SECURE Act, however, provides an exception for certain beneficiaries, including disabled or chronically ill beneficiaries. In these situations, a disabled or chronically ill beneficiary (or special needs trust for their benefit) may qualify as an eligible designated beneficiary and benefit from a prolonged distribution over the life expectancy of the beneficiary.

Special needs trust and account beneficiary designations should be carefully drafted by qualified estate and tax planning professionals to ensure that the special needs trust is an eligible designated beneficiary. Moreover, the special needs trust should only permit the beneficiary who is disabled or chronically ill during their lifetime to receive distributions so that the trust will qualify to use the life expectancy of that individual for RMDs.

The Secure 2.0 Act was enacted on Dec. 29, 2022, and provided greater clarity for special needs trusts to be eligible designated beneficiaries and to benefit from the prolonged lifetime distribution periods.

## **4. ABLE Accounts**

ABLE Accounts can be a useful addition to special needs planning. These accounts are owned by the disabled person and can be managed by the disabled person or someone else on their behalf. Contributions to the account from all sources per year cannot exceed \$17,000 in 2023, except that some working disabled persons may be able to contribute more. Additionally, ABLE Account balances over \$100,000 count toward the \$2,000 asset limit for SSI. Similar to a d4A trust, there is a Medicaid payback at the death of the account owner. Final regulations were issued in October 2020. The uses, restrictions, and differences between ABLE Accounts and d4A trusts are complex and beyond the scope of this brief chapter.

For more information, you should consult with