

CHAPTER 14

SPECIAL NEEDS TRUSTS AND ABLE ACT

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. They have created The Arc's Center for Future Planning, which has resources to help disabled people and their families create future plans. 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. SSI, SSDI AND MASSHEALTH DEFINITIONS

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 a medically determinable physical and/or mental condition(s) that has lasted or is expected at least 12 continuous months or result in death. There is a separate disability definition for children. 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 of SSI the recipient will receive, 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.

In April of 2024, the Social Security Administration published a final rule, "Expansion of the Rental Subsidy Policy for Supplemental Security Income (SSI) Applicants and Recipients." As of Sept. 30, 2024, food is no longer considered "In-Kind Support and Maintenance" (ISM) for SSI purposes. This new rule also extends the same advantageous policy to all SSI applicants and recipients nationwide that was previously only available in seven states due to judicial decisions. This change may increase the benefit amount some people are eligible to receive and will allow more people to qualify for critical SSI payments. SSA also implemented several other rules in 2024 to simplify applying for and accessing SSI benefits.

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. 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 all 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.

3. 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 below); 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 seek qualified counsel to review their situation.

B. 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.

C. 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 flexibility and control over assets as well as protection for the disabled adult's government benefits. The assets held in a properly drafted special needs trust are for the disabled adult and are generally used to supplement the disabled adult's needs that are not paid for with government benefits. Trustees use their discretion to manage and distribute assets on behalf of the disabled adult.

D. TYPES OF SPECIAL NEEDS TRUSTS

1. **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 that trust for the beneficiary. The assets did not originate from the beneficiary. These types of trusts can be established by a third party during life by creating a trust or at death by a third party's will (testamentary trusts). Creating a trust during your lifetime allows family members to give gifts during their lives to the trust and designate the trust as a beneficiary of accounts or receive a portion of inheritances. Conversely, a testamentary trust is created by your will and does not exist until the testator's death. Therefore, it is not a viable beneficiary until that time. The terms of the special needs trusts can include the ultimate disposition of the assets once the

beneficiary passes away (e.g., the remaining assets can go to other family members).

2. **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 are not considered a countable resource. In order to be properly established, this special needs trust must: 1) be established by the disabled individual, a parent, a grandparent, a legal guardian or the court; 2) be funded prior to the disabled beneficiary attaining age 65; and 3) provide a payback provision noting that the Commonwealth of Massachusetts and other states that have provided benefits 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.
 - a. **d4C trusts are another type of self-settled trust.** These 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.
 - b. **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.
 - c. **Currently, pooled trusts are available to persons of any age.** MassHealth attempted to limit this planning option for individuals over age 64 as of March 1, 2024. However, through legislative advocacy, that limitation was reversed. Individuals over age 64 are able to use this planning option again as of Dec. 6, 2024. Individuals should consult with knowledgeable disability and 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.

E. 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 payback provision as a self-settled trust (as discussed in Section D).

F. THIRD-PARTY SPECIAL NEEDS TRUSTS AS BENEFICIARIES OF RETIREMENT PLANS

When individuals attain a certain age, they must 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 ("EDB"). 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 EDBs and to benefit from the prolonged lifetime distribution periods, including allowing remainder beneficiaries of a special needs trust to be a charity.

G. 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 \$19,000 in 2025, 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. The uses and restrictions of ABLE Accounts and d4A trusts, and the differences between them, are complex and beyond the scope of this brief chapter.

For more information, you should consult with an elder law attorney.

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