



SPECIAL NEEDS PLANNING

Planning for the future is a responsibility that all families face, but when you have a loved one with special needs, it becomes even more critical. Special Needs Planning is about securing the financial, emotional, and legal well-being of your loved one, ensuring they have the best possible quality of life.

Social Security Benefits

Social Security plays a crucial role in supporting individuals with disabilities in the United States. To be eligible for benefits, the individual must meet the Social Security Administration's (SSA) definition of disability, which involves having a physical or mental impairment that prevents an individual from engaging in substantial gainful activity and is expected to last for at least 12 months or result in death.

The Social Security Administration (SSA) offers two main programs to assist those with disabilities: Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). SSDI provides financial support to individuals who have worked and paid into the Social Security System but are unable to continue working due to a disability. SSI, on the other hand, is designed for individuals with disabilities who have limited income and resources. Both programs aim to provide financial assistance and access to essential healthcare services, offering a safety net that helps individuals with disabilities maintain a basic standard of living and quality of life.

A disabled child may qualify for benefits under their parents' work record when certain criteria is met. To be eligible, the child must have a disability onset before the age of 22.

- **Parent's Eligibility:** The adult child must have a parent who is either currently receiving Social Security retirement or disability benefits or who is deceased but had sufficient work credits to enable the child to claim survivor benefits.
- **Dependency:** The adult child must demonstrate dependency on the parent's Social Security earnings record, either financially or by being unmarried and having a disabling condition that began before age 22. The adult child must be unmarried, as marriage may affect eligibility for benefits on the parent's record.
- **Work Activity:** The adult child should not be engaging in substantial gainful activity (SGA), which means their earnings should not exceed the SGA threshold set by the SSA. SGA levels are adjusted annually.

The Medicaid Program

Navigating the world of healthcare and benefits can be challenging, especially for individuals with disabilities and their families. Medicaid, a vital program, offers a range of support and services tailored to the unique needs of individuals with disabilities.

- **Healthcare Coverage:** Comprehensive healthcare services, including doctor visits, prescriptions, therapies, and more.
- **Home and Community-Based Services (HCBS):** Support for independent living, personal care, and assistance with daily activities.
- **Behavioral Health Services:** Access to counseling, mental health care, and substance abuse treatment.

- **Long-Term Care:** Assistance for those needing nursing home or assisted living facility care.
- **Vocational Support:** Programs to help individuals with disabilities find and maintain meaningful employment.
- **Transportation Services:** Help with getting to medical appointments, work, and community activities.
- **Assistive Devices:** Coverage for necessary medical equipment and assistive technology.
- **Dental and Vision Care:** Access to oral and eye health services.

Protecting Benefits

Navigating the intricacies of public benefits can be challenging, especially when trying to preserve eligibility while managing personal or family finances. One key tool in this arena is the Special Needs Trust (SNT), designed to hold assets for the benefit of an individual with disabilities without affecting their eligibility for means-tested benefits like Medicaid or Supplemental Security Income (SSI). These trusts can pay for a variety of life-enhancing expenditures without compromising benefit eligibility. There are two primary types of Special Needs Trusts: the Self-Settled Special Needs Trust and the Third-Party Special Needs Trust.

- **Self-Settled Special Needs Trust:** This type of trust is funded by the person with disabilities themselves. It allows them to set aside assets, often through an inheritance, personal injury settlement, or other means, without jeopardizing their eligibility for means-tested government benefits like Medicaid or Supplemental Security Income (SSI). The assets in this trust can be used to supplement their quality of life by covering expenses not covered by these benefits, such as education, transportation, or entertainment. Under federal law, these trusts are subject to a Medicaid payback.
- **Third-Party Special Needs Trust:** This type of trust is funded by individuals other than the person with disabilities, such as parents, grandparents, or other family members. This trust enables family members to contribute assets while ensuring that the loved one with disabilities can continue to receive essential government benefits. It offers peace of mind, knowing that their financial support can enhance the disabled individual's life without compromising their eligibility for critical assistance programs.

A SNT may be a single trust managed by a Trustee, or a **Pooled Special Needs Trust**. A Pooled Special Needs Trust allows multiple beneficiaries to pool their resources for investment and management purposes, although each beneficiary has their own separate account, called a sub-account. This can lead to lower administrative costs and potentially better investment returns due to the larger collective balance. Pooled Trusts, under federal law, are established and managed by nonprofit organizations that have expertise in both managing the trust funds and understanding the needs of individuals with disabilities. A Self-Settled Pooled Special Needs Trust ensures that upon the death of the beneficiary, any funds remaining in a sub-account are retained by the nonprofit organization in lieu of repayment to Medicaid. When the trust holds assets that exceed the potential reimbursement to the state Medicaid program, then payback will be made and the remaining funds will be paid to the designated remainder beneficiary of the sub-account.

Another crucial instrument is the **ABLE account**, a tax-advantaged savings account that can be opened for individuals whose disability occurred before they turned 26. Contributions to ABLE accounts can be made by anyone and can be used for qualified disability expenses. These accounts have annual contribution limits but offer the beneficiary more control over funds while still preserving their public benefits.

Surrogate-Decision Making

Surrogate decision-making for someone with a disability involves appointing an individual (the surrogate) to make decisions on behalf of a person with a disability who is unable to make those decisions themselves. This can cover a range of decisions, from medical treatment and care options to financial and legal affairs.

Before a surrogate is appointed, an individual's capacity must be assessed to determine whether the individual has the capacity required to designate their own surrogate. To appoint their own surrogate, the individual must understand the nature and effect of a **Power of Attorney** and **Advanced Medical Directive**.

These legal documents allow individuals with disabilities to designate someone to make financial and healthcare decisions on their behalf.

When an individual is incapacitated, which means that they are incapable of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that the individual lacks the capacity to (i) meet the essential requirements for his health, care, safety, or therapeutic needs without the assistance or protection of a guardian or (ii) manage property or financial affairs or provide for his support or for the support of his legal dependents without the assistance or protection of a conservator, then the appointment of a surrogate occurs through a **Guardianship** and **Conservatorship** proceeding. A guardianship typically pertains to personal and healthcare decisions, wherein a guardian is appointed to make choices regarding the individual's living situation, medical care, and overall well-being. Conversely, a conservatorship is concerned with financial affairs, granting a conservator the authority to manage the individual's finances, assets, and property. These roles are often assumed by family members, friends, or court-appointed professionals and carry the responsibility of acting in the best interests of the protected person, ensuring their needs are met and their rights are upheld. Regular oversight and reporting to the court are required to maintain transparency and accountability in the guardianship or conservatorship arrangement.

Even with surrogate decision-making, it's important to involve the person with a disability in decisions to the greatest extent possible, respecting their autonomy and rights. It is important to note that when an individual's specific wishes are known, the surrogate uses the "substituted judgment" standard to make decisions as the person would have made. If the wishes are not known, the surrogate uses the "best interest" standard, making choices that are believed to best promote the well-being and quality of life of the person with a disability.

Other Considerations

Although protecting public benefits eligibility is usually on the forefront of a plan for an individual with a disability, it is about much more. Some other things to consider include:

- **Estate Planning:** Tailor your estate plan to provide for your loved one both during your life, especially upon your own disability, and at your death.
- **Financial Planning:** This involves creating a budget that takes into account the individual's current and future needs. In many cases, it will involve assessing what additional financial support will be necessary. Parents or caregivers often consider life insurance to provide financial support after they are gone.
- **Letter of Intent (LOI):** An LOI is a non-binding document that provides a future caregiver with insights into the individual's personal history, preferences, and the specific nature of their care. It acts as a guideline for providing consistent and informed care.
- **Employment and Vocational Considerations:** For those who are able to and interested in working, planning may involve vocational training and understanding how employment income may affect public benefits.
- **Housing Considerations:** A plan must be developed to provide for appropriate and sustainable living arrangements. This may involve looking into special housing programs.
- **Education and Advocacy:** Develop strategies for securing appropriate educational services and advocating for your child's needs.
- **Community Resources and Support:** Connect with organizations and services that can support your family's unique journey.

Not only do laws and individual circumstances change, requiring the plan to be reviewed and updated regularly, but you should ensure that all family members are aligned with the plan and understand how their actions (like gifting money directly to an individual) can impact public benefits.

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