

Special Needs Planning

Establishing Future Care for Loved Ones and Peace of Mind

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Special Needs Planning

Developing a Life Care Plan - Overview

“A life care plan is a blueprint for providing the economic security and services that someone with special needs will require in order to live a fulfilling life, as independently as possible. The Plan is an evolving document that:

- Assesses the supports that will be required, and their cost, given the individual’s disabilities and desired lifestyle;
- Identifies government benefits for which the person may be eligible;
- Includes a financial plan for supplementing publicly-provided services, including a special needs trust (SNT) if means-tested government benefits will be required;
- Recommends guardianship or powers of attorney, if the individual will be unable to make important decisions independently;
- Suggests a letter of intent containing medical, education and personal details to guide caregivers when parents have passed away.” SNA.org

Two Considerations:

1. Guardianships & Alternatives

2. Special Needs Trusts

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1. Guardianships

A guardian is a court appointed surrogate decision maker and advocate for a special needs individual (“ward.”)

- **Basic Guardianship Duties (in-part):**

- “Make and communicate important decisions about the ward’s life affairs and well-being based on what the ward would decide if capable of making the decision;
- Make decisions that ensure the health and well being of the ward, based on what the ward would decide if capable of making the decision;
- Seek information about the ward’s value system, wishes, and needs from the ward, the ward’s family, friends, or legal documents such as a Living Will;
- Involve the ward in all decisions to the extent possible;
- Allow the ward the opportunity to exercise rights that are within his/her comprehension and judgment, allowing the ward the same possibility for error as a person who is not incompetent;
- Support the ward in developing the necessary skills to assume responsibility for his/her own decision-making (e.g., training, education, employment, habilitation, and/or rehabilitation, etc...);
- Periodically review the guardianship and consider alternatives to guardianship (e.g., restoration to competency or limited guardianship.” See *Guardianship Duties*, Disability Rights North Carolina

Special Needs Planning Guardianships

Note: Guardians owe a fiduciary duty to the ward. The guardian must make decisions in the ward's best interest. While a guardian's decision may supersede a ward's wishes and wants, the guardian and ward relationship is not hostile!

- **Life Affairs- 4 Primary Areas:**

- **Health Care:** Honor written advance medical health care instructions. Give consent/approval necessary to enable the ward to receive medical, legal, psychological, counsel, treatment, or appropriate services. Obtain expert medical/mental consultation when needed. Arrange for regular medical & dental examinations for good health & required annual status reports.
- **Finances:** Manage the ward's financial affairs, pay owed debts, taxes, and necessary expenses, and submit applicable accounting/status reports, protect ward's property, etc....
- **Residence/Housing:** Establish the ward's residence (e.g., private home/facility, community-based, treatment facilities, group homes, etc...)
- **Associations/Relationships:** Manage the ward's personal and business associations/relationships.

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Lesser Restrictive Alternatives to Guardianships

- Social Security Representative Payee (SSI, SSDI, Medicaid)
- Special Needs Trusts
- Property Power of Attorney
- Health Care Power of Attorney



Special Needs Planning **Guardianships**

Guardianship vs. Power of Attorney

Guardianship

- Court Supervised
 - Yearly accountings
- Public
- Expensive
- DMAT required
- Terminates person's rights

Power of Attorney

- No Court Supervision
- Private
- No DMAT
- Individual must have capacity to understand document
- "Adds" to person's rights

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2. Special Needs Trusts

“A special needs trust (SNT) is a legal vehicle enabling assets to be held on behalf of someone with disabilities without affecting their eligibility for means-tested public benefits such as Medicaid or Supplemental Security Income. While assets held by the trust are not “countable” for the purpose of qualifying for such programs, there are strict regulations regarding disbursements. SNTs are meant to supplement the funds and services available through government programs.” See Special Need Alliance Org.

- A special needs trust acts as a firewall between beneficiary and \$\$\$
- \$\$\$ can be spent on quality of life expenditures (e.g., Trips, activities, entertainment, employment training, education, vacations, etc...)

Special Needs Trust

What is a Trustee?

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Administering a much needed special needs trust is complicated, but necessary. A trustee is responsible for, in-part:

1. Avoiding activity that conflicts with the purpose of the trust—which is to enhance the quality of life of the beneficiary;
2. Investing and managing trust property, following the terms of the trust and state law, in the beneficiary's best interests;
3. Spending money to enhance the beneficiary's life, while making the trust funds last as long as possible;
4. Keeping the beneficiary and other interested persons up to date on trust activity;
5. Working together with the beneficiary's guardian or conservator, if court appointed;
6. Responding to beneficiary's personal needs for goods and services not covered by SSI or Medicaid;
7. Ensuring compliance with SSI/Medicaid income/resource rules, so trustee spending doesn't affect beneficiary's SSI/Medicaid eligibility;
8. Keeping accurate records, preparing required SSI/Medicaid reports, and filing necessary federal and state tax returns;
9. Zealously advocate and defend the trust by requiring SSI and Medicaid programs to comply with applicable law;
10. Terminating the trust, if circumstances warrant doing so;
11. Managing or distributing the trust property after the beneficiary dies or the trust is terminated.

Special Needs Trust

What is a Trustee? – Cont'd

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These responsibilities require an understanding of government programs, including strict regulations concerning the use of SNT assets, since improper use of funds can disqualify the beneficiary for important means-tested public benefits.

* **Note:** A trustee owes a fiduciary duty to the beneficiary. A trustee's most fundamental legal duties are to act honestly, advocate, and place the beneficiary's interests above his own. The trustee should have a deep appreciation for the beneficiary's needs and desires so that the trust will make the best possible contribution to the individual's quality of life.

- A trustee has an affirmative fiduciary duty to be proactive in identifying a beneficiary's needs and using trust funds to improve the beneficiary's quality of life. It is not proper, nor sufficient, for the trustee to merely prudently invest the trust's funds and safeguard its assets; these actions, while reasonable on their face, defeat the foundational purpose of the trust- to provide the beneficiary care and improve quality of life. *See generally J.P. Morgan Chase Bank, N.A., Mark C.H. Discretionary Trust of 1995 v. Marie H.*, 956 N.Y.S.2d 856 (N.Y. Surr. Ct., 2012).
- **Who Can be a Trustee of a SNT? 1)** Person (be cognizant of age); **2)** Corporation; or **3)** Combination of both
- **Who CANNOT be a Trustee of a SNT?** The child with a disability



Special Needs Trust

3 Types of Special Needs Trusts

1. First (1st) Party Trust
 - Person with the disability
2. Third (3rd) Party Trust
 - Parent/grandparent, *etc...*
3. Pooled Trust
 - Managed by a non-profit association

Special Needs Trust

3 Types of Special Needs Trusts

1st Party Special Needs Trust:

- A first party, or self-settled, SNT is created with assets belonging to an individual with disabilities, who becomes the “beneficiary.”
- Funds typically consist of an inheritance or personal injury settlement.
- The person must be under 65 at the time that the trust is established.
- Funds remaining in the trust at the beneficiary’s death must be used to reimburse Medicaid for services to that individual before they can be distributed to anyone else.

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3 Types of Special Needs Trusts

3rd Party Special Needs Trust:

- A third party special needs trust is created with assets provided by anyone *other than the beneficiary*, such as parents, grandparents, relatives or friends of the beneficiary.
 - Note: Do not leave assets directly to the beneficiary with disabilities! Ensure assets are left to the SNT. (e.g., grandparent's gifts, life insurance, inheritance, assets, etc...)
- Such a trust can be created and funded during the life of the originator ("inter vivos") or as part of a last will and testament ("testamentary").
- Trust funds (\$\$) are distributed according to trust document
- Upon the beneficiary's death, there is no requirement to use residual funds to reimburse Medicaid for services provided to the individual, and "remainder" beneficiaries may be named to receive those assets.

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3 Types of Special Needs Trusts

Pooled Special Needs Trust: - Good option for small amounts of \$\$

- A pooled SNT is often a practical alternative for small estates or where it is difficult to identify a trustee.
- Pooled Trust is a SNT established by a non-profit association that serves as Trustee
- Non-profit establishes a beneficiary sub-account.
 - Sub-accounts belonging to many beneficiaries are managed as a single entity, usually by nonprofit corporations that call upon the experience of social workers, money managers and special needs attorneys.
 - Since many financial institutions do not handle small SNTs, or charge fees that are not cost-effective for modest trusts, pooled trusts can give families access to highly skilled trustees.
- Funds remaining at the beneficiary's death are typically divided between Medicaid and the nonprofit/Pooled Trust to help others with disabilities.

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Avoid the Avoidable!

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- Actions Steps:

- Plan for the future! DON'T BURY YOUR HEAD IN THE SAND!

- Contact a local Special Needs Alliance Atty in your state:

- <https://www.specialneedsalliance.org/find-an-attorney/>



Glut1
Deficiency
Foundation

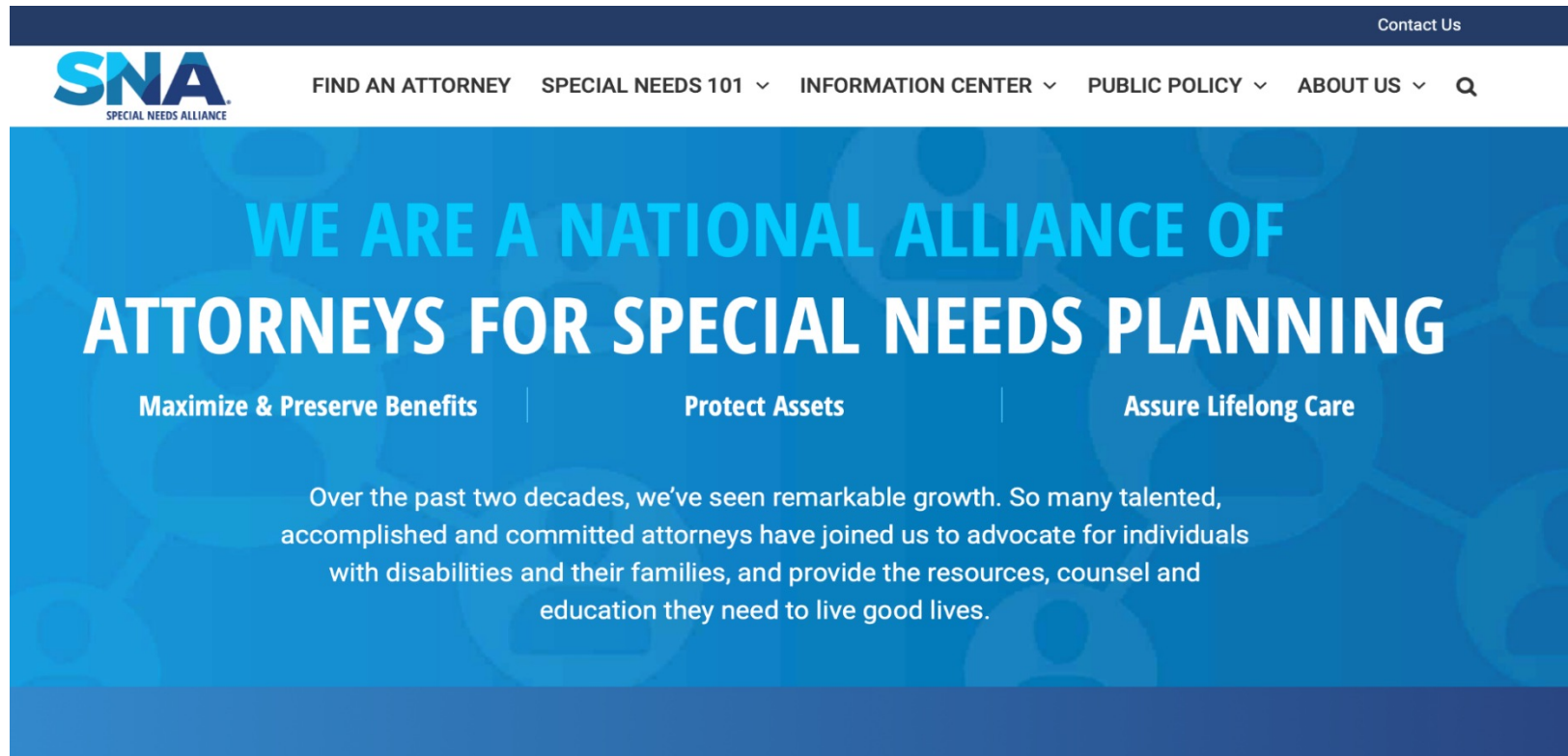
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References and Important Links

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Special Need Alliance, Org:

The Special Needs Alliance (SNA) is a national organization comprised of attorneys committed to the practice of disability and public benefits law. Individuals with disabilities, their families and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena. See <https://www.specialneedsalliance.org/>



The screenshot shows the homepage of the Special Needs Alliance (SNA). At the top right, there is a "Contact Us" link. The main navigation bar includes "FIND AN ATTORNEY", "SPECIAL NEEDS 101" (with a dropdown arrow), "INFORMATION CENTER" (with a dropdown arrow), "PUBLIC POLICY" (with a dropdown arrow), and "ABOUT US" (with a dropdown arrow), followed by a search icon. The SNA logo is on the left. The main content area has a blue background with the text "WE ARE A NATIONAL ALLIANCE OF ATTORNEYS FOR SPECIAL NEEDS PLANNING". Below this, three key areas are listed: "Maximize & Preserve Benefits", "Protect Assets", and "Assure Lifelong Care". A paragraph of text follows: "Over the past two decades, we've seen remarkable growth. So many talented, accomplished and committed attorneys have joined us to advocate for individuals with disabilities and their families, and provide the resources, counsel and education they need to live good lives."



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References and Important Links

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- **Life Care Planning:**
 - <https://www.specialneedsalliance.org/special-needs-101/life-care-planning/>
- **Special Needs Trusts:**
 - <https://www.specialneedsalliance.org/special-needs-101/special-needs-trusts-and-personal-injury-settlements/>
- **2022 Special Needs Trust Trustee Handbook:**
 - <https://www.specialneedsalliance.org/wp-content/uploads/2022/01/2022-SNA-Handbook.pdf>
- **Government Benefits:**
 - <https://www.specialneedsalliance.org/special-needs-101/government-benefits/>
- **Special Education:** <https://www.specialneedsalliance.org/special-needs-101/special-education/>
- **529A (ABLE) Accounts (Educational Account similar to 529 College Plan):**
 - <https://www.specialneedsalliance.org/special-needs-101/able-accounts/>
- **Helpful Links for Families and Individuals with Special Needs:**
 - <https://www.specialneedsalliance.org/special-needs-101/additional-resources/>

* Information and statements also compiled from *Special Needs Planning* PP, Amanda E. Tarzwell, Esq., Law Office of Gayle F. Tarzwell, Wakefield, RI.

