**When Should I Update my Child's Special Needs Trust?**

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Estate planning for a child with special needs is not a one and done transaction, but an ongoing process. As your child with a disability evolves, so should the special needs trust (SNT) designed to enhance that child's life.

If you're reading this and you don't have a special needs trust for your child, now is the time to contact a Special Needs Alliance attorney in your state to guide you through this vital planning process. If you're reading this and you have an estate plan that includes an SNT for your child, when did you last review your plan? Do you know if your plan still makes sense and who the key players are?

You should revisit your estate plan and special needs trust periodically as life changes occur, and at the very least every three to four years. If the SNT is irrevocable, consult your attorney about whether and how it can be modified.

**What life changes might necessitate updates?**

- Change in your or your child's health and/or independence;
- Change in your child's public benefits (Supplemental Security Income (SSI), Medicaid, Section 8 Housing);
- Death or incapacity of a Trustee, Guardian, or Family Member;
- Move to a new state or country;
- Purchase of real estate, especially if it's located in another state;
- Change in financial situation; and
- Change in laws or tax regulations.

Even if there have been no major life changes in recent years, periodic reviews ensure that your child's SNT and your estate plan still align with current rules and best practices. This review should also include an assessment of how your assets will sync with your plan and whether your chosen fiduciary will know what steps to take.

**How Does my Child's Special Needs Trust Work?**

In the most basic terms, a Special Needs Trust is an agreement. It's a written agreement between a person who creates and adds property to the trust (Grantor) and the person who

agrees to hold and manage the trust property (Trustee), and the trust document outlines how the trust property will be used for the benefit of the person with a disability (Beneficiary).

If you have an SNT for your child with a disability and will be funding that trust with your assets at death, either under your Will or Revocable Trust, through a transfer on death (TOD) designation or deed, payable on death (POD) designation, or beneficiary designation, you likely have a third party Special Needs Trust (often called a Supplemental Needs Trust). When properly drafted, funded, and administered, this type of trust can hold funds for your child without disqualifying them from receiving SSI, Medicaid, and other needs-based public benefits. The assets in the SNT will be managed by a Trustee, who will make decisions about how the funds are invested and spent on your child's needs. If your child passes before the funds are exhausted, the remainder will pass to the people or charities you name, and a properly funded third-party SNT is not subject to the Medicaid payback requirement that applies to first-party SNTs.

One of the most important aspects of your child's SNT is the choice of Trustee. Do you recall who the Trustee of your child's SNT is? Are you naming a trust company or bank or an individual to serve as Trustee? Who is the successor Trustee? Do you have a Trust Protector or Trust Advisor? Trust administration is where many plans succeed—or fail. Having the right Trustee is one of the best ways to ensure that your intentions will be followed and your child's SNT will be administered in the way you envisioned.

A trust company or bank with SNT administration experience should know how to make distributions that will not negatively impact a beneficiary's public benefits, how to coordinate payments with an ABLE account, how to mitigate taxes and file necessary tax returns, and how to hire the right professionals to ensure your child's needs are being met. However, depending upon the circumstances, a family member may be capable of serving as Trustee with the right support. Talk with your special needs law attorney about the pros and cons of naming a corporate Trustee or whether you may want to have family members serve in other roles in your child's SNT and your overall estate plan.

**What Else Should You Revisit?**

You may have created a Trustee Memo or Letter of Intent (LOI) when you established an SNT for your child. An LOI is a document written by the Grantors of the Trust (usually one or both parents of the child with a disability) that expresses their vision for how the SNT should be used to enhance the Beneficiary's life. It serves as a nonbinding guide for the Trustee to carry out your vision and does not change the trust's terms. It can also include your wishes regarding your child's support needs, housing, and preferred care managers and medical providers. Clear guidance may avoid family conflict and ensure continuity during the transition.

**Key Aspects to Address and Update**

**1. Housing and Living Arrangements -** Housing needs are often complex, and planning should be thoughtful and realistic.

**Questions to consider:**

- Is your child living at home, independently, or in a supported setting?
- Will your child need group home placement in the future?
- Should the SNT own or help fund housing?

Your LOI should describe your child's housing needs and preferences and discuss a backup housing plan if the current arrangements fall through. Review with your attorney whether the trust authorizes purchasing or maintaining a home and how housing payments may affect benefits, including possible reductions in SSI. Housing rules tied to benefits (especially SSI) can change periodically, so outdated provisions may unintentionally reduce support.

**2. Guardianship and Decision-Making –** If you are serving as Guardian or Conservator for your child, it is critical to nominate in your estate plan a successor Guardian or Conservator, as applicable, subject to court appointment under state law, or in some states, to have a court order naming a successor or standby Guardian and Conservator.

**Questions to consider:**

- Is the current designated Guardian still appropriate and willing?
- Should you move toward supported decision-making instead of full guardianship?
- Are the successor Guardians clearly named in your estate plan or court order?

**3. Medical Care and Advocacy**

No one knows more about your child's health needs than you do. It is vital that your SNT Trustee and future Guardian have access to your child's medical history and preferences so they can support and advocate for your child.

**Questions to consider:**

- Have your child's diagnoses, medications, or care providers changed?
- Does your child have specialists or long-term therapies?
- Who will advocate for them in emergencies?
- To what extent can they make their own healthcare decisions?
- Would it make sense to use SNT funds to hire a case manager?

**A Practical Approach**

An outdated Special Needs Trust can create gaps in care, reduce benefits, or cause unnecessary stress for the Beneficiary and/or future caregivers. Think of your estate plan and Special Needs Trust as part of a broader life plan to protect your family. Your estate plan isn't just about documents — it's about making sure the right people, with the right guidance and resources, can step in at the right time. Regularly review the plan with your special needs planning attorney, financial advisor, and (when appropriate) your family. Keeping your plan current helps maintain your child's housing, medical care, financial stability, and personal well-being when they need it most.

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