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Future Planning Starter Guide

Special needs trusts in plain language: the three kinds families meet most often, how they compare side by side, the shelter and cash rule that surprises everyone, and the questions to ask before you choose one.

From the guide at transcenders.app/special-needs-trusts/
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The problem these trusts solve

Most disability benefits are means tested. If a person receiving SSI or Medicaid holds more than a small amount of money in their own name (for SSI, the resource limit is $2,000 for an individual), benefits can stop. A special needs trust holds money for the person's benefit without that money counting as their resource, so the benefits continue and the trust pays for the extras that make life better: things benefits do not cover.

There are three kinds of special needs trust families meet most often. They differ in whose money goes in, who sets the trust up, and what happens to what is left at the end.

Kind 1: Third party special needs trust

- **Whose money:** someone else's. Parents, grandparents, or other family members fund it with their own money or leave money to it in their will.
- **Who sets it up:** the family member whose money it is.
- **Payback:** none. Because the money was never the beneficiary's, the state has no claim on what remains. Leftovers pass to whoever the trust names.
- **Good to know:** this is the trust that lives inside many parents' estate plans. It can be created during the parents' lifetime or at their death, and anyone can add to it.

Kind 2: First party special needs trust

Set out in federal law at 42 U.S.C. 1396p(d)(4)(A).

- **Whose money:** the disabled person's own money. Common sources: a legal settlement, an inheritance received outright by mistake, back pay, or court ordered support structured into the trust.
- **Who sets it up:** a parent, a grandparent, a legal guardian, or a court. The beneficiary cannot set up their own (d)(4)(A) trust, even as a competent adult.
- **Rules:** the beneficiary must be under 65 when the trust is established and funded, and must meet the Social Security definition of disabled. The trust must be irrevocable and for the person's sole benefit.
- **Payback:** yes. At the beneficiary's death, the state is repaid for Medicaid benefits paid over the person's lifetime, before anything passes to family.
- **Who runs it:** a trustee the family chooses. A family member can serve, which keeps fees low, but the trustee takes on real duties: vendor payments only (never cash to the beneficiary), careful records, tax filings for the trust, and protecting benefits with every disbursement. Professional trustees charge for the same work and carry insurance and staff.

Kind 3: Pooled special needs trust

Set out in federal law at 42 U.S.C. 1396p(d)(4)(C).

- **Whose money:** the disabled person's own money, like Kind 2.
- **How it works:** a nonprofit organization runs one master trust. Each person joins it with a joinder agreement and gets a separate sub-account in their own name. The funds are pooled only for investment and management; the accounting for each person stays separate.
- **Who sets it up:** a parent, grandparent, guardian, the court, or the person themselves. This is the one first party route a competent adult can join on their own signature.
- **Rules:** no under 65 funding deadline of the (d)(4)(A) kind applies the same way in practice for joining, the disability standard is the same, and each sub-account must be for the person's sole benefit.
- **Payback:** yes, with one difference. At death, amounts remaining in the sub-account may first be retained by the nonprofit's trust, to the extent the trust's documents and the joinder provide, and the state is repaid from the rest up to the lifetime Medicaid total.
- **Who runs it:** the nonprofit is the trustee. It reviews every disbursement request against the benefits rules, reports to benefits agencies, sends accountings, and handles the trust's tax work.
- **Fees:** pooled trusts charge for this work. Typical structures include a one time enrollment fee, an annual administration fee that is often zero or low at small balances and rises with the balance, a small investment fee, and a termination fee. Ask for the full fee schedule in writing before joining (see the question list in this guide).

Side by side

Question	Third party	First party (d)(4)(A)	Pooled (d)(4)(C)
Whose money goes in	Family's money	The person's own money	The person's own money
Who can set it up	The family member funding it	Parent, grandparent, guardian, or court	Parent, grandparent, guardian, court, or the person
State payback at death	No	Yes	Yes, after any amount the nonprofit trust retains under its terms
Who is trustee	Whoever the family names	Whoever the trust names	The nonprofit
Typical cost shape	Attorney drafting fee	Attorney drafting fee, plus trustee and tax costs over time	

			Enrollment fee plus annual administration and investment fees
Minimum amount	None set by law	None set by law	Most pooled trusts set a minimum balance

The rule that surprises everyone: shelter and cash

A special needs trust is for supplemental needs, the extras beyond what benefits provide. Two kinds of payment can reduce SSI even when they come from a properly built trust:

- Cash to the beneficiary counts as income.
- Payments for food and shelter (rent, mortgage, utilities, groceries) count as in-kind support and maintenance and reduce SSI by a set amount, up to a cap.

Sometimes paying for shelter is still the right choice, because housing matters more than the reduction. The point is that it must be a choice, made with the numbers in view, never an accident. This is also why trustees pay vendors directly and keep receipts for everything.

> **Using a trust and an ABLE account together:** an ABLE account (in California, CalABLE) can pay for housing and food without that SSI reduction, which is why many families use a special needs trust and an ABLE account together: the ABLE account for monthly living costs, the trust for everything else and for amounts above the ABLE limits.

Questions to ask any pooled trust before joining

- ☐ What is the full fee schedule: enrollment, annual administration at my expected balance, investment, tax preparation, transaction, and termination fees?
- ☐ What minimum balance must the account keep, and is the enrollment fee taken from the first funding or charged on top of it?
- ☐ Who must be involved in signing the joinder? (Many pooled trusts require an attorney to advise the family and sign. Ask what that costs and whether they keep a referral list.)
- ☐ How do disbursement requests work, who may submit them, and how long does approval usually take?
- ☐ What can the trust not pay for, in writing?
- ☐ How are accountings provided, how often, and how long do I have to object?
- ☐ At death, what share of the remainder may the trust retain, and can I choose a lower share, including zero?

- ☐ If a court will order payments into the trust (for example, support payments), what must happen first, and how do the paying agency's transfers get directed to the sub-account?
- ☐ Are the master trust and fee schedule current, and will you confirm that in writing?
- ☐ If I want to leave, what are the termination rules and fees?

Questions to ask before choosing a family trustee

These questions are for a first party trust, where the family picks the trustee.

- ☐ Will the trustee pay vendors directly, every time, and keep receipts and a ledger that a benefits agency could audit?
- ☐ Who prepares the trust's tax return each year, and what does that cost?
- ☐ Does the trustee know which payments count as food and shelter, and will they check before paying?
- ☐ Who reports changes to the benefits agencies, and on what timeline?
- ☐ Who is the successor trustee, and would they have complete records if they had to step in tomorrow?
- ☐ Does the trustee understand that at the beneficiary's death, the state must be repaid before family receives anything?

Where a pooled trust comes from, if you want to dig deeper

Pooled trusts exist because Congress created them in 1993 (Omnibus Budget Reconciliation Act of 1993, adding 42 U.S.C. 1396p(d)(4)(C)) so that people with disabilities could protect benefits without each family drafting its own trust. The trustee must be a nonprofit organization. Social Security reviews pooled trusts against its policy at POMS SI 01120.203; if a trust's documents fail the rules, its sub-accounts can be counted as resources, which is why established nonprofits with long track records run most of them.

A note on getting advice

This guide is education, not legal advice, and it is not a substitute for a special needs planning attorney in your state. The cost of drafting or joining the wrong structure is measured in lost benefits, and most families need one good consultation more than they need ten articles. If your situation involves a settlement, an inheritance already received, or court ordered support, talk to an attorney before the money moves, because several of these structures must exist before the funds arrive to work at all.

Keep going

Read the full guide online: this starter guide comes from Transcenders' plain language guide to special needs trusts, which is updated as rules change. Find it at transcenders.app/special-needs-trusts/

Not sure where your family starts? The free Family Navigator walks you through benefits, school, and services step by step and builds a checklist for your family. Start at transcenders.app/family-navigator/

Transcenders Inc is a nonprofit. This guide is free, and you are welcome to print and share it with other families.

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