

ESTATE PLANNING AND TRUST ADMINISTRATION



Special Needs Trusts Q&A With Jacqueline Rahn

We recently sat down with Jacqueline Rahn, head of family office fiduciary services, to discuss how parents and other relatives can provide for loved ones with disabilities or who require ongoing care. People in this position may consider special needs trusts, which are purpose-built to complement public assistance, even after the person who establishes the trust is gone.

In the interview that follows, Jacqui defines the three types of special needs trusts and how they could help maintain or improve quality of life for their beneficiaries. She also shares questions families should ask as they explore their options, common mistakes to avoid and more.

What is a special needs trust, and what role does it play in long-term planning?

A special needs trust is designed to supplement rather than supplant public benefits.

It's meant for individuals who rely on programs such as Social Security or Medicaid that have income and asset limits. The trust allows someone to remain eligible for those benefits while also providing resources for things those programs may not cover.

Public benefits generally provide for essentials such as housing, food, clothing and medical care. A special needs trust can help pay for things outside those basic necessities—education, entertainment, travel, transportation or other opportunities that can improve quality of life.

What are the different types of special needs trusts?

There are three types of special needs trusts.

A **first-party** or **self-settled special needs trust** is when the beneficiary uses their own assets to fund the trust. We often see this when someone inherits money but advance planning wasn't done. While this type of trust can preserve eligibility for benefits, it comes with a payback provision. When the beneficiary dies, any remaining assets may have to be used to reimburse the state for benefits received during their lifetime.

The type of trust we see most often is a **third-party special needs trust**. That's when a parent, grandparent, sibling or other family member creates the trust for the benefit of a disabled individual. These trusts don't have the same payback provision, and other family members can contribute to them over time.

The third type is a **pooled trust**. These are generally administered by nonprofit organizations that manage funds for multiple beneficiaries. They can be a good option for people who don't have the resources to create and administer their own trust.

One of the most important aspects of these trusts is that the trustee controls distributions. The beneficiary generally can't demand money from the trust, and payments should typically be made directly to a vendor rather than to the beneficiary. If the trust is buying a car, for example, the trustee would write a check directly to the dealership. The whole point is to keep the money out of the beneficiary's hands so it doesn't interfere with benefit eligibility.

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When should families begin thinking about a special needs trust?

If you have someone in your family who is currently receiving means-tested public benefits—or who may need those benefits in the future—it's worth considering whether a special needs trust makes sense.

It could be apparent at birth if a child has special needs and will require lifelong support. The need could also arise later because of an illness, accident or progressive condition.

There are also situations where someone isn't receiving benefits because their parents are still able to support them, but the family anticipates that benefits may become important in the future. That's when planning ahead can be especially valuable.

How can a special needs trust support a loved one's quality of life?

One example that always comes to mind is a beneficiary I worked with whose trust funded an annual vacation with her caregiver. Every year they would go to Disney World, the beach or somewhere else she enjoyed visiting.

It was a really special tradition, and without the trust she wouldn't have been able to do it. Her parents thought it was important that she have those experiences and opportunities despite her disability.

That's a good illustration of how these trusts can enrich someone's life. They can help pay for travel, visits with family members, group activities, enhanced medical care or better living arrangements. A trust could even purchase a home or apartment for someone if that's what's best for them. There are a lot of ways these funds can improve quality of life.

What are the most important decisions families make during the planning process?

One of the biggest decisions is selecting the trustee.

These trusts can be complicated because the trustee needs to understand benefit programs, eligibility requirements and the rules that govern them. That's one reason I often think it makes sense to have a professional trustee involved.

Another thing I encourage families to consider is creating what's often called a memorandum or side letter. It's separate from the trust document and isn't legally binding, but it gives future trustees a much more complete picture of the beneficiary.

It can describe the person's personality, preferences, limitations, daily routines, likes and dislikes, and the family's vision for their future.

Trusts often continue long after the person who created them is gone. Future trustees may not know the beneficiary personally, so having that guidance can be incredibly helpful.

How should families think about selecting a trustee?

A trustee should understand special needs trusts, public benefits, tax issues and the administrative requirements involved. There are often ongoing eligibility reviews, reporting requirements and paperwork associated with benefits programs, so it helps to have someone who has the resources and experience to manage those responsibilities.

Personally, I'm a strong advocate for having a professional trustee serve alongside a family member or close friend whenever possible.

The professional trustee can focus on the legal, tax, accounting and administrative responsibilities, while the family member provides a personal understanding of the beneficiary and their needs.

It's really the best of both worlds.

What are some important conversations families should have during this process?

One conversation that comes up frequently is how assets should be divided when there is one disabled child and other children who are not disabled.

In many estate plans, children are treated equally. With special needs planning, families sometimes have to think differently about what's fair and what resources each child may need in the future. Those can be difficult but important conversations.

It's also important to talk with people who are already involved in the beneficiary's life—caregivers, educators, health care providers and others who understand the person's needs. They often have valuable insight into what support may be needed now and in the future.

What are some common mistakes families make?

One of the biggest mistakes is doing no special planning at all and leaving assets outright to a disabled beneficiary.

Another common mistake is disinheriting the beneficiary because of concerns about preserving public benefits. Historically, some families felt they had to choose one or the other. Today, special needs trusts often make it possible to preserve benefits while still setting aside resources for the beneficiary.

I also think it's important to work with an attorney who specializes in special needs planning. These trusts have very specific requirements. If they're drafted incorrectly, the beneficiary could end up losing eligibility for benefits, which defeats the purpose of creating the trust in the first place.

How often should these trusts be reviewed?

As a general rule, I think reviewing the trust every 10 years is a good benchmark. That's similar to how people think about reviewing estate plans more broadly.

That said, families should revisit the trust sooner if there are significant changes in the beneficiary's condition, their benefits or their circumstances.

The goal is simply to make sure the trust remains aligned with current regulations, best practices and the beneficiary's needs.

What's one piece of advice you wish every family knew before beginning this process?

Keep the plan as flexible as possible.

Parents naturally want to protect children with special needs. Sometimes they want to reach out from the grave. They want to make sure everything is taken care of.

But trying to be too controlling can actually limit a plan's effectiveness. It's important to think carefully about the beneficiary, their needs and your vision for their future while also recognizing that circumstances will change and there's only so much you can predict.

One way to build flexibility into a plan is through a contingent or optional special needs trust provision. That allows a trustee to evaluate the circumstances later and decide whether creating a special needs trust makes sense at that point in time.

I also think it's important not to become so focused on preserving benefits that you lose sight of the beneficiary's overall well-being.

Sometimes a distribution might affect a particular benefit but still dramatically improve a person's quality of life. You have to look at the situation holistically and ask what's truly in the beneficiary's best interests.

That's why flexibility is so important. You simply don't know what the situation is going to be when the plan eventually plays out.

Thank you for your time and insights, Jacqui!

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