



## Thriving with special needs

*With thoughtful planning, you can help ensure the future care of a loved one with a disability*

**T**o live a full life, and attain some measure of security and happiness – this is what all good parents want for their children, including those with sons and daughters who have disabilities. The difference is that families caring for a child with special needs often require special care to color in the details and make that dream a reality.

If you're the parent or relative of someone with special needs, you've probably wondered what you can do to make sure your loved one is taken care of no matter what. Here's a look at ways to build a better tomorrow for your beloved child with the help and advice of professionals you trust, including a new option to create tax-free savings accounts for children with special needs.

### **A different shade of 529**

The Achieving a Better Life Experience (ABLE) Act of 2014 created the federal framework that allows parents to fund long-term care for a disabled child in a tax-free savings account (similar to a 529 account), for the life of the child.

The funds are held in a way that preserves eligibility for Supplemental Security Income (SSI recipients must have less than \$2,000 in assets) and potentially Medicaid assistance. You may already be aware, but these types of means-tested benefits come with tricky rules for eligibility. That's why it's important to consult a financial professional before gifting assets to a person who relies on government benefits.

Most states are still working on the rules for these accounts, with Virginia being the first to implement a qualified

program. However, families everywhere welcome this important option to help them plan for the future.

### **Knitting a safety net**

If you or someone you know is caring for someone with special needs, you've probably heard about special needs trusts, a common financial and estate planning tool. These third-party trusts are structured so the beneficiary doesn't own the assets directly, allowing continued eligibility for need-based government benefits, such as Medicaid and SSI. The trust can be funded with just about any type of asset: securities, real estate, cash. Some parents leave the trust empty until funded by the proceeds of their life insurance policy; others use it right away to set aside money for their child.

## Other types of trusts

### First-party special needs trusts

Another consideration is the source of funding. We've already talked about third-party trusts, but if your child has assets of their own, either from a legal settlement or an inheritance from a well-meaning relative unaware of means-tested benefits, a first-party special needs trust might be in order.

These self-settled trusts allow the beneficiary to safeguard eligibility for public benefits. The trust requires that the beneficiary be younger than 65 at the time the trust is funded, be disabled per the definition in the Social Security Act, and that the trust agreement includes a provision that reimburses the state Medicaid agency upon death of the beneficiary.

### Pooled trusts

You might also consider a pooled trust run by a nonprofit organization. These trusts combine and invest the funds of individuals with special needs, maintaining a separate sub-account for each participant from which they receive distributions. This protects Medicaid and other benefits eligibility, and has a lower setup cost. Unlike third- and first-party special needs trusts, a disabled person can sign an agreement on their own behalf to join a pooled trust.

The pooled trust makes distributions to the beneficiary until the account is empty or the beneficiary passes away. Any funds left in the sub-account will be used for other trust participants or will be used to reimburse the state for Medicaid payments.

Most parents use these trusts because they feel government benefits aren't enough to give their child an adequate standard of living (in 2015, the basic monthly SSI benefit was \$733 for an individual, meant to cover food and shelter). But they realize these same benefits allow their child access to valuable educational classes and outreach services that require Medicaid eligibility. Another reason for a trust: There's no guarantee that government benefits will continue or be able to provide their loved one with a safe, comfortable lifestyle. With a trust and

benefits, there are at least two sources of income and more security for a person who may not have a way to earn a living.

That's why the structure of the trust is so important: The funds are designed to supplement, not replace, the government benefits. If funds from the special needs trust are used to pay for the beneficiary's food or shelter or if a beneficiary receives cash outright, that could trigger a reduction or loss of benefits. That's why the trust is best used to pay for goods and services that Medicaid doesn't cover (e.g., a handicap accessible van, dental treatment or special therapies), for travel and cultural experiences, or anything else that would add to your child's quality of life. Any remaining funds can be used as an inheritance for another family member.

### A maestro for your plan

Administering these types of trusts can

be complex, so choosing the right trustee is crucial. This person will be given absolute control over the distribution of trust assets, be mindful of the beneficiary's disabilities, be assertive about claiming entitlements, and invest the trust funds wisely. On top of all this, the trustee also must keep up with any laws regarding trusts and public benefits.

It's a lot to ask of a family member, and with so much at stake, many families choose to appoint a professional as sole trustee or co-trustee. Another option is to have a financial professional work with family members in a trust advisory committee that has the power to recommend distributions to the trustee or replace the trustee if needed. Keep in mind that trustees commonly receive a fee for serving, as allowed by state law.

### A stand-in guardian

For most parents, choosing a successor guardian is a crucial but difficult part of the estate planning process. After all, if full guardianship is needed, you are essentially asking someone to fill your shoes, taking care of all social, emotional, physical, educational and medical needs for your loved one when you no longer can. Maybe that's a brother or sister or a favorite cousin; just be sure to choose a trustworthy adult who only has your child's best interests at heart.

Once you've chosen a guardian, be sure to detail your preferences and instructions through an official will, though a court must still confirm the appointment. Parents should also name a backup guardian just in case.

Once you know who will take care of your child, if and when you can't, you'll want to figure out where they'll live. Do you want your child to remain in the home he or she grew up in and have the guardian move in? Or would your

**11.2 million children  
in the U.S. have special  
healthcare needs.**

Source: National Survey of Children with Special Health Care Needs

child move into the guardian's home? There are also group homes, apartments, planned residential communities and healthcare facilities for those who need more involved care. And you'll want to explore these options well before they're needed, to determine what's best for your loved one.

Keep in mind that changes in tax laws or regulations may occur at any time and could substantially impact your plans. That's why it's best to discuss any tax or legal matters with the appropriate professional.

### Caring for those who need it most

For most parents of a disabled child, ensuring total care of their loved one is their life's work, perhaps becoming even more important when they're no longer able to provide the care themselves. Working with a financial advisor and other professionals on the bigger financial picture can provide a sense of ease, knowing you've done all you can to protect and provide for someone you love. It just takes some extra planning to bring a colorful vision of a special needs future to life.

You'll want to explore living options well before they're needed

## A place of their own

Adults with developmental disabilities have options when it comes to finding a sustainable living arrangement, including modern co-ops that allow for independence in a supportive environment. If you're considering one of these options, make sure to start planning the transition as far in advance as possible. Abrupt changes can cause unnecessary stress, so plan visits to where your loved one might live and have them spend quality time with any potential roommates or caregivers.

### Living with a family member

Arranging for a sibling or other relative to provide a backup home is often the go-to choice. In choosing a successor guardian for an adult with special needs, it's wise to be frank with the person about the responsibilities that accompany this role. The Special Needs Alliance has prepared a helpful guide ([specialneedsalliance.org](http://specialneedsalliance.org)).

### Living with a foster family

If you are seeking a close-knit environment but don't have many family members available to pitch in, you may want to look into state agencies that can help you place your child with a family that is equipped and able to take care of an adult with disabilities.

### Living with a group

Group homes run the gamut, but the majority of these facilities have a trained caregiver onsite 24 hours a day to support residents. Many group homes have a long waiting list, leading some families to band together and form their own group homes.

### Living in a planned residential community

These developments are designed to maximize autonomy and community inclusion for adults with disabilities in a co-op-style living situation. An example is The Arc Village in Jacksonville, Florida, which broke ground in November. There are similar communities across the country. For information, visit [ltoventures.org/communities-to-watch/](http://ltoventures.org/communities-to-watch/).

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