



# Heart to Heart

A Newsletter for Parents of Children with Disabilities

"...that their hearts may be encouraged..." Colossians 2:2

"Therefore I tell you, do not be anxious about your life, what you will eat or what you will drink, nor about your body, what you will put on. Is not life more than food, and the body more than clothing? Look at the birds of the air: they neither sow nor reap nor gather into barns, and yet your heavenly Father feeds them. Are you not of more value than they?" Matthew 6:25-26



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## Financial and Estate Planning for Children With Special Needs

by Deb Gordon

Parents of children with special needs know that each day brings small and large victories. Parenting children with special needs also comes with unique challenges, including increased financial responsibilities and more complex planning requirements for the future. The cost of therapies, medical procedures, equipment and caregiving—on top of wages lost as a result of caretaking duties—can be daunting. Because these children may continue to require care into adulthood, sound financial and estate planning is essential to ensure they're cared for even after you're gone.

Try not to get overwhelmed at the thought of financial planning for a child with special needs. This guide is focused on helping you plan one step at a time, learn what help is available and talk to other parents in your situation. A sound strategy can help you take concrete steps to manage your finances and gain peace of mind for your child's financial future.

### Steps to Creating a Plan for Your Child With Special Needs

Planning for an uncertain and expensive future can be daunting. Parents of children with special needs often worry about who will care for their children and how their children will manage when they're gone.

"Once you become a parent, you worry about everything," says Valerie Zaloom Buccino, Esq., an attorney specializing in estate planning, special needs planning and guardianship. "This worry never ends, but for parents with children with special needs, this worry takes on a much different meaning."

Though all parents need to plan for their children's future, parents of kids with special needs have to take

more steps than others. Breaking down the tasks and tackling them over time can help you feel less perplexed.

### Step 1. Find Your Community

Parents who are living through similar circumstances can provide emotional support and a wealth of information. Finding your community where special needs families can search for advice, referrals and moral support is vital.

"Parents in a similar situation are going to be the most capable of directing people," Dania Ermentrout, a case manager in North Carolina's Medicaid program and parent of a medically fragile daughter, said. They may have already solved the exact problem you're facing. Ermentrout also recommends finding or starting a Facebook group to connect with other parents of kids with similar diagnoses. "That's where I get most of my survival tips," she said.

Christine Lai, founder of the Special Education Legal Fund and a parent of a child with autism, also recommends finding community online. "The Internet is obviously a great thing," Lai said. "But for families with special needs, it is a tremendous resource that people outside of the community might not understand. For a family that doesn't know anyone, no one in their circle has had this experience, or maybe they live in a remote area, this is a real lifesaver."

### Step 2. Assess Your Financial Situation

Most people need to adjust to the level of expenses required to care for children with special needs. The first step in an effective plan is a realistic assessment of your current situation. Start asking and seeking

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answers for questions such as:

- Do you have assets to pay for your child's expenses?
- Do you have debts you need to manage?
- Can you scale back on other spending to make room for new costs?

These questions may not have easy answers, but putting some thought into them will help you build your plan on a solid foundation.

### **Step 3. Learn the Landscape**

Explore these vital programs and resources for kids with special needs, even if you think you don't qualify.

#### **MEDICAID**

Medicaid covers care for children with disabilities, typically under Medicaid waivers specific to each state. Visit KidsWaivers or your state's Medicaid agency to learn about programs where you live.

#### **MEDICARE**

Better known as insurance for older Americans, Medicare also covers some younger people with disabilities. If you qualify for Social Security disability benefits, you can enroll in Medicare Part A, which covers hospitalization, and Part B for doctor visits and medical equipment.

#### **SOCIAL SECURITY DISABILITY BENEFITS**

The Social Security Administration provides cash benefits for children with disabilities and adults who became disabled before age 22 via Supplemental Security Income (SSI). SSI may be used for food, clothing and housing. Applying and qualifying for SSI or SSDI requires an extensive process, and your child must meet clinical criteria.

### **Step 4. Speak With Trusted Experts**

Parents who have a child with disabilities speaks with a financial advisor

Navigating education, insurance, finances and the legalities of raising a child with special needs is complex. It's a good idea to consult expert financial advisors, special needs attorneys and special education advocates. Ensure they have expertise in special needs issues and relevant programs such as Medicaid, Medicare and Social Security.

### **Step 5. Set Goals**

Set short- and long-term goals for your financial plan and then expect to adapt. When parents of a 5-year-

old with special needs asked Buccino how to plan for their child outliving them, she answered, "We have to take this a step at a time. An estate plan will have to change as your child gets older."

She tells clients to plan for today, but be ready to adjust and amend the plan as things change. "Kids with special needs often achieve more than we dare to hope for," Buccino says. "I've seen it time and time again. So we prepare for the worst, and once everything is in place, I ask them to put it aside, and allow yourself to hope for the best."

### **Step 6. Build Short- and Long-Term Strategies to Meet Your Goals**

For many parents with children with special needs, it helps to consider short- and long-term needs when making plans for their children.

#### **SHORT-TERM STRATEGIES**

Parents may face lost income resulting from the time required to care for their children. In a two-earner household, assess which parent's income is larger and more stable and who has access to better health benefits. If one parent decides to stop working outside the home to care for a child with special needs, both parents must acknowledge the loss of income and professional purpose for the parent who is suspending their career.

Based on potentially decreased income and increased expenses, build a budget and financial plan for the anticipated costs, and if possible, a cushion for unanticipated expenses. Look at your current health insurance coverage, and maximize your health savings or flexible savings account if you have one.

Families facing the cost of therapies, medical procedures and caregiving typically need to seek assistance and public benefits to help cover costs.

Waiting lists for services can be years long. Even if you qualify for benefits, there may be waitlists for programs like residential facilities or expert evaluations. Get organized to start the process as soon as you can.

#### **LONG-TERM STRATEGIES**

Estate planning is important for all parents, but when you have kids with special needs, it is essential. Consult an attorney to develop an estate plan that should, at a minimum, include a will, health care proxy and power of attorney. These

documents let you specify what should happen and who should care for your child if you die or become incapacitated. Discussing your wishes with family members or close friends can be difficult but will ultimately help protect your child in the future.

You may also want to write a letter of intent, an important estate planning document that does not require a lawyer. This type of letter documents your child's needs and provides instructions for anyone who may need to care for them if you cannot.

Life insurance and retirement savings are important components of a long-term financial plan. Though you may find it challenging to save for the future, if you possibly can, you will contribute to your family's financial health over time.

### Step 7. Get Organized

Gather personal information for you and your child, including:

- Birth certificates, Social Security numbers and insurance policy information.
- Usernames and passwords for online services including banks, patient portals, investment accounts and social media accounts.

- Emergency contacts.
- Medical information such as names and locations of doctors and hospitals, diagnoses, medications, equipment and allergies.
- Financial information including investments, asset information, financial advisor information, information on your income and expenses like mortgages or other debts.
- Legal documents such as a power of attorney and will.

These details can help in a crisis when the last thing you want to worry about is finding your passwords or making sure family members can access your key information.

Build your repository of information one step at a time, so it doesn't overwhelm you. Just imagine how much better off you'll be to have your information together if you need help.

Article continues with tools, tips, and further resources. Please visit: <https://www.moneygeek.com/financial-planning/resources-for-parents-of-children-with-special-needs/>



## Support Groups

Contact us at **717.859.4777**  
or visit [hvmi.org](http://hvmi.org) for details.



Join other parents of "children" (of any age) with disabilities for fellowship, sharing, prayer and encouragement from God's Word at our **PIP (Parents In Progress)** Support Group meetings:

### South Jersey — Medford, NJ

4th Monday, 6:30–8:00 PM (October-May)  
(Bible Club program available during meeting time for children, teens and adults with a disability.)

### Lancaster County — Akron, PA

2nd Monday, 7:00 PM (October-May)



## H\*VMI Upcoming Events

- October 2**      **Chicken BBQ and Fall Fun Family Event**, Akron PA
- October 8–9**    **H\*VMI Yard Sale**, Akron PA
- October 29**    **\*Lancaster County Area Ministry Luncheon**, Shady Maple, East Earl PA
- November 13**   **\*North Jersey Area Ministry Luncheon**, River View Banquet Center, Berkeley Heights NJ

Contact H\*VMI for details and \*reservations.

*"Therefore do not worry about tomorrow, for tomorrow will worry about itself.  
Each day has enough trouble of its own."*

*Matthew 6:34 (NIV)*

I don't know about you, but there are times in my life I get bogged down with planning and expectations. There are so many big unknowns in life, so it can feel better to focus on the details and smaller things. It makes me feel in control to map out my driving route down to the last stop sign, but more often than not, I hit construction, road blocks, or detours! Ironically, I find that I am typically more annoyed when my plans are made and then thwarted, rather than if I didn't have any plans to begin with! Planning and preparation are certainly necessary in life. The Lord calls us to be prudent with our blessings and wise stewards with all we are given. Children are often a catalyst to get your finances and future plans in order—especially when our children have different futures than what we envisioned. There's nothing wrong with making plans—and it's necessary for a more peaceful future! However, we shouldn't

get bogged down with the details and forget to look to the Ultimate Planner for wisdom and grace. We need to thank Him for the opportunity to make the plans, look to Him for the wisdom to set the plans in motion, and then *let go of any idea of permanent plans* and let God do the rest. God is perfectly good and perfectly all-knowing. That means that sometimes our plans fit perfectly well in His design, and sometimes He takes control and gives us a detour with an even better destination. I may not always be thrilled in the midst of the alternate route. It's painful to have our plans "ruined" and no longer feel sure of our way! But regardless of our circumstances, we can rest in the knowledge that the Lord is fully sovereign in all things! The big struggles, the tiny details, or the financial worries—He cares deeply about **all** aspects of our lives.

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For more information, please contact  
**Christine Whiting at:**

**H\*VMI**  
PO Box 122  
Akron PA 17501-0122

**717.859.4777**

Email: [cwhiting@hvmi.org](mailto:cwhiting@hvmi.org)

Website: [hvmi.org](http://hvmi.org)

Editor: Christine Whiting



## Parents In Progress

is a group designed just for parents of children with disabilities, offering resources to help them as they raise and nurture their children; and providing a "safe" environment of support and encouragement where they can freely discuss the issues unique to their families.

*"PIP is the one place I can truly express my frustrations because I know everyone there understands and cares."*

Please feel free to contact **Heart to Heart** regarding articles, resources, or information contained in this publication. We also welcome your thoughts, personal testimonies, articles, and resources that would be helpful or encouraging to other parents!