The Need for Financial Planning for Special-Needs Kids

There are many types of financial worries, but probably none as relentless as the costs of treating and supporting a special needs child.

A 2008 MassMutual/Easter Seals study focusing on autism spectrum disorders (ASD), a range of conditions that can lead to problems with socialization, communication and behavior, discovered the following:

- Nearly three-fourths of parents are worried about their children's financial future after they're no longer able to care for them.
- Only 40 percent of children with ASD had designated a guardian or created a will; only 20 percent have created a special needs trust.
- Seventy-four percent of parents with autistic children do not have a life care plan for their children.
- Health insurers pay for services only 39 percent of the time, leaving families with autistic children to take on more debt than parents who don't have kids with disabilities.

According to a study released in December by the U.S. Centers for Disease Control, an average of one in 110 children have ASD. For parents affected by these conditions or other physical, emotional or developmental disabilities in their children, financial planning should be part of the response. That's why it's a good idea to bring in trained expertise, including financial, legal, tax and estate help shortly after diagnosis. A financial planner is a good first step.

There are planners who specialize in special needs issues for family members of all ages. PlannerSearch, a service provided by the Financial Planning Association®, can help sort planners by expertise and location. Here are some common financial planning activities that parents of special needs kids should explore:

The retirement and estate plans should come first: Even though one or both parents undergo a massive lifestyle change to support their disabled child – a responsibility not unlike a second career – they can't forget planning for retirement and healthcare needs. It's very easy for parents to sacrifice their lifestyle needs when a child is sick or disabled, but personal planning is essential, and it should come before planning activities for the child.

This personal planning needs to go well beyond retirement savings. Parents need immediate estate planning to make sure their assets are properly disbursed for the specialized care of their minor or adult children when they die – an event that can happen at any time. The first step of the process is making a will with specific directives for the child as well as yourself if you are incapacitated and can't make decisions for the child. A financial planner can walk parents through this parallel process of personal financial planning and planning for the child.

Then move on to the special needs child: A child can have no more than $2,000 in total assets to qualify for federal benefits, so special planning is necessary. It's particularly important to make sure that the child not be named a direct beneficiary of any assets that would put him over the $2,000 figure at any point in time, so it's important that proceeds from life insurance, IRAs, annuities, 401(k) s, 403(b) s and any other inherited assets be placed in something called a Special Needs Trust.

Special Needs Trusts can be set up to accumulate, manage and disburse monies for any child with a disability. (There are also Community Trusts, which are trusts set up by nonprofit institutions that perform the same function – see which option fits best.) The trust itself becomes the beneficiary of any inherited assets, and with very few limitations won't affect the child's eligibility for government benefits. Parents also need to consider whether or not to go through the guardianship/conservatorship process to take legal/financial control of their children's lives. In the case of a minor child, generally guardianship or conservatorship will terminate when the child turns 18 or, in some states, upon marriage if the child marries before age 18. Then, obviously, parents need to decide whether a disabled child needs a trustee other protections to carry him through adulthood and beyond their deaths.

Depending on your situation, it's a good idea to research a supplemental needs trust, which are written to provide benefits to and protect the assets of physically and mentally disabled individuals while allowing them to continue their qualifications for a variety of government-provided healthcare benefits under Medicaid.

It's best to locate attorneys who specialize in special needs issues to write these trust agreements and coordinate with your planner and tax and estate professionals.

Don't forget your other kids: When a disabled child becomes part of a family, parents have an added responsibility to make sure their non-disabled children aren't ignored. That goes for financial issues as well. Because disabled children represent a significant financial burden, it's doubly important to get planning help to make sure you can afford college and other essentials for the rest of your offspring.

September 2010 — This column is produced by the Financial Planning Association, the membership organization for the financial planning community, and is provided by Marnie Aznar, MBA, CFP ®, a local member of FPA.