

Special Needs Trusts: Estate Planning Is Crucial for Ensuring the Future of Your Autistic Child

By Shannon King Nash, Esq.

Jane and Mark Ramsey are an average family¹. They have two kids - Jennifer age 12 and Jimmy age 3. Their assets include a house valued at \$200,000 (but with no equity), two cars together worth \$15,000 and a \$100,000 life insurance policy. Jane and Mark have a combined gross income of \$100,000. They also have 401k plans and stock worth \$35,000. Recently, they learned that Jimmy has autism. Since they aren't rich, they don't think they need sophisticated estate planning vehicles like special needs trusts, right?

The Ramey's need to think again. Every parent of a developmentally challenged child needs to invest in careful planning to protect their child's future. The less the family has, the more tragic are the consequences of a failure to plan.

What's the Big Deal?

Supplemental Security Income (SSI) is the federal needs-based program that many disabled children and adults may be eligible for if they meet certain income limits. SSI beneficiaries may also get Medicaid (medical assistance) to pay for hospital stays, doctor bills, prescription drugs, and other health costs. However, once a person's income exceeds \$2,000 a year, they are no longer eligible for SSI or Medicaid.

Over \$13 billion is spent annually to care for individuals with autism. For the average affected family this translates into \$30,000 per year. Many parents believe that needs-based programs like SSI and Medicaid will take care of their child when they are gone. This is a common misconception.

Take our family the Ramseys. Jimmy's inheritance will have to be completely spent before he's eligible for the needs-based programs. With Jimmy's half of his parent's estate (about \$75,000), he will be forced to spend all but \$2,000 of his inheritance before he becomes eligible for a single dollar of assistance. And he may be forced to spend most of this on health care expenses. At this rate, Jimmy will have exhausted his inheritance in less than three years. So much for the nest egg that the Ramsey's had hoped to leave.

Even families who believe their child won't need government assistance (for example, a family with a million dollars in assets) this could still be a problem. Their child will probably not be able to qualify for private health insurance after the parents are gone and perhaps before depending on their employer's health insurance policy. Medicaid might be the only way for their child to get needed health care services. But this child will not qualify for Medicaid because of his huge inheritance. With people living longer and the costs for care of autistic people increasing, this huge inheritance will likely be completely spent long before the parents had hoped - leaving the child to spend his later days in poverty.

¹The Ramsey's are a fictional couple and are being used to illustrate some of the points in estate planning for special needs children.

The Money Issue

Although there is no bright line rule for when a parent needs a special needs trust, many families should have one. Special needs trusts are probably not necessary for parents living at the poverty level, which was \$18,100 for a family of four in 2002. These families are already on government assistance and the kids will continue on this assistance even after their parents' death.

But for the majority of American families - those earning about \$65,000 a year for a family of four - a special needs trust is crucial. These families typically have very little in tangible assets, second mortgages on their homes, and little to no savings (likely due to paying for costly therapies). But even though they are not wealthy, their children aren't used to relying on government assistance. And they often have life insurance (mostly term life insurance or employer provided), which may be valuable. Estate planning vehicles like special needs trusts can ensure that this life insurance will in fact be available to retain their child's quality of life.

Special Needs Trust

A special needs trust is a vehicle that provides assets from which a disabled child can maintain his quality of life, while still remaining eligible for needs-based programs that will cover basic health and living expenses. Here's how it works: the Ramseys create a special needs trust to benefit Jimmy that provides instructions as to the level of care they want for him. They also create a will that leaves certain assets to the special needs trust - no assets are left directly to Jimmy. After they are gone, the people they have chosen to manage the trust (trustees) can spend money on certain defined expenses for Jimmy's benefit without compromising his eligibility for needs-based programs.

In general, basic living expenses such as food and shelter may not be provided for through the special needs trust. But essential quality of life expenses such as clothing, vocational training, facilitative technologies and travel (both around town and long distance) may be provided. Certain health care expenses that are related to the person's disability (occupational therapy, speech therapy, etc) may also be provided for by the trust. However, more universal health care expenses such as nonprescription vitamins and antibiotics may not be provided. Parameters vary from state to state so parents should check with a qualified attorney in their state. (See Side Bar for questions to ask a prospective attorney and information on how to find an attorney in your area).

Crucial choices you will need to make in establishing a special needs trust include:

Trustee

The trustee can be a family member or close friend who knows your child and who is organized, financially savvy and above all ethical. Some families opt for a professional trustee (usually working for banks or financial institutions). Whatever the choice, it's crucial for the trustee to understand the expenses that can and can't be provided for under the special needs trust.

Purpose of the Trust

This provision should enumerate all of the reasons for establishing the trust and might include the following issues:

- Where should the child live? (i.e., a group home vs. assisted living at home)
- What specific social activities should be supported by the trust? (e.g. special Olympics, choir, religion)
- What specific technologies or treatments should the child have access to?
- With whom should the child have regular contact facilitated by the trust? (e.g. plane tickets and other travel arrangements)

Revocable

Special needs trusts may be completely revocable (altered) at any time. But there are disadvantages to revocability. Revocable trusts can create higher taxes at death since they are included in the parents' gross estate for purposes of the estate tax. Also revocable trusts can create a problem should circumstances change, like one parent dies and the new spouse wants to change the terms of the special needs trust. One solution might be to make the trust irrevocable when formed such that it cannot be changed. But parents should consider putting an "irrevocability trigger provision" into the revocable trust. Basically, the irrevocability trigger kicks in when the change occurs - such as death of a parent, divorce, or when the trust's assets reach an amount that is likely to cause a huge estate tax burden.

Others Estate Planning Vehicles

Special needs trusts work best with an integrated estate plan. A will or similar vehicle that directs which funds will go into the special needs trusts is essential. But make sure to understand how the special needs trusts works with the will. A "stand-alone special needs trust" is created during the parents' lives and can be funded by the parents though provisions in their will. Also other family members like grandparents may make contributions to this trust. However,

if the special needs trust is contained inside the parent's will, known as a "testamentary trust", it doesn't actually exist until the parent dies. In that case, only the parents or those who die after them can fund this trust.

In addition to a trustee who manages the financial aspects under the special needs trust, the parents should also consider appointing a guardian who will manage the day to day care of their child. Although they can be the same person, parents should include as many loving people as possible in caring for their child with autism.

- Finally, a letter of intent or a life plan that details the parents' wishes for their child may be helpful. While these life plans are very useful in keeping the child's care as close as possible to normal, they are not legal documents. In fact, they do not have to be followed by the child's new guardian. But because life plans provide very valuable detailed information, they are often used in conjunction with other estate planning vehicles.

Recap

Whatever estate planning vehicle(s) is used, it is important to set up something before it is too late. With only a few hours of careful planning, the Ramseys have ensured that Jimmy will be able to maintain his quality of life after they are gone.