

Providing Financially for your Special Needs Family Member

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Summary

If you have a child, sibling, or other family member who is cognitively or physically disabled and unable to provide for him/herself financially, you have a more complex retirement situation than most. There are two basic strategies that can work: impoverish your family member so that he or she will qualify for government benefits, or enrich him or her enough not to have to depend on government benefits.

Note: Just to simplify the grammar, let's assume that the disabled dependent in question is your child – very similar issues apply if it is a sibling or someone else you care about.

Focusing on money

Money is not really the biggest problem.

If you are already in this situation, you know what the real problems are: getting adequate medical care and therapy; finding facilities or individual care workers to help with daily activities and supervision; enabling your child to have a life that is interesting and challenging and rewarding up to the abilities he or she does have; providing for safety and care even when you're not there, and especially if he or she outlives you, or you become too old or disabled yourself to handle it.

If you could be sure of all these things, you would not need much money for your dependent child. And indeed, the state will take care of him or her if you do not have money. But while money is not the main problem, it can be a big part of the solution. If you have enough money, you can provide for these things yourself while you are here and even after you are gone. Perhaps you have no choice about this, but perhaps you do.

Plan 1: Letting the state provide

Special needs children, generally up to the age of 22, are provided for through local school districts, generally with financial support from the state and federal government. Inevitably, the quality of services varies greatly from place to place.

Once such children reach adulthood, the level of care they receive is even more random and unpredictable. The lucky ones have parents or other relatives with whom they can live. During the day, they may get state-supported transportation to a job site or to an adult daycare facility, so that the family caretakers have time to make their own living and to take care of other aspects of their own lives. Sometimes disabled adults can live in group homes or foster homes, though there are not nearly enough of these facilities, and those that exist are not always of high quality. State agencies will generally try to help find jobs, residences, social services, and transportation, but the need greatly exceeds both the availability of these items and the ability of the states to pay for them.

Disabled adults are generally entitled, starting at age 18, to Social Security disability benefits (SSI). But these top out at \$698 a month (in 2012) and are reduced if the recipient is able to earn any money from work. Eligibility also ends if the recipient accumulates more than \$2,000 in financial assets of his or her own. But even with these restric-

tions, SSI benefits are a great boon to the disabled, and can generally pay for food, clothing, and incidentals ó though not for housing, medical care, or supervision. States do provide varying levels of medical care for the disabled, though.

The *financial* implication of all this is: if you want the state to take care of your disabled child, you must *impoverish* that child. She or he cannot own any substantial financial assets, or have any regular source of significant income.

The *care* implication is that your child will be at the mercy of the state for as long as he or she lives. This is far better than not having any care at all, but it is far from ideal:

- Although state agencies will usually pay a lot of attention to what the child's parent (or other legal guardian) wants, many decisions are ultimately in the hands of state workers. Most of them are caring people, but they are often overworked, are stifled by bureaucratic rules, and are limited by tight budgets and a lack of good facilities and services to choose among.
- When you are gone, your child will be even more at the mercy of people you don't know.
- State support, in coming decades, is probably going to get worse rather than better. On the one hand, the ranks of the disabled are growing faster than the general population (autism and Alzheimer's disease, for instance, are increasing by leaps and bounds). Meanwhile, in addition to the huge budget deficits and national debt our society already faces, we are looking at potential future crises in Social Security and Medicare as the Baby Boomers start moving into retirement in big numbers. There is going to be enormous competition for whatever government monies exist in the future for care for the sick, disabled, and indigent.

For the past two decades, the standard advice from financial planners for parents and guardians of the disabled has been to impoverish them and to make sure they stay impoverished, thereby qualifying them for government entitlements. This is indeed at least a marginally acceptable plan, but it is chancy, especially if your child outlives you. Your child will be better off if she or he is not at the mercy of society as a whole, and of state agencies that are already over-stretched and likely to become more so in the future.

But if relying entirely on state benefits is, or has to be, your plan, you still need to do it right. Make sure you understand the financial rules, which your state agency for the disabled can explain to you.

Plan 2: Making your child financially independent

Although many families do not have this option, many do.

In some cases, it may not apply. If your child has a condition that greatly decreases his or her life expectancy, your main problem may be providing for him or her during what is expected to be a limited number of years, not so much what will happen when you are gone. In these situations, your concerns may be paying for doctors, hospitalizations, prescription drugs, specialized therapy, or even just supervision and recreation. If this is your situation, and you are around to manage your child's life, then you may be best off

to keep your child poor for now, obtain whatever government benefits you can get, and then supplement those out of your own pocket as well as you can.

If your child is likely to outlive you, though, you have more to think about. It can often (but far from always) be best to think about caring for her or him in three stages:

- ***While your child is living with you:*** this is essentially the same situation described just above. Your child probably does not need his or her own assets, and will probably benefit from SSI payments, state-provided transportation, respite, and other benefits you may be offered.
- ***If/when your child needs placement elsewhere:*** your child, as an adult, is not legally your responsibility any more. If her or his condition is too severe, or you yourself become elderly or ill, or you simply cannot both work and take care of your child, a residential placement may be necessary, and the state will do what it can. But generally there are limits to what the state can pay, and if you want the best placement for your child, you are more likely to get it if you can pay for all or some of it yourself.
- ***When you are gone:*** you will no longer be able to supervise the care your child receives. Perhaps you have a well child, or someone else in the family who will do it for you, but you are lucky indeed if you have someone who will do as a good a job as you. So the more you are able to provide financially for your child, to pay for her or him to receive good guardianship and to live a good life with good care in a good residence, the more confidence you can have that all will be well.

The more you and your child age, therefore, the more beneficial it is to find ways to make him or her financially independent of state care.

Can you have it both ways?

If you and/or other relatives have enough money to help your child some, but not enough to make her or him completely financially independent, you may still be able to make arrangements that work. Assets can be placed into a supplementary special needs trust (described in more detail later), so that your child does not actually own them. The child then qualifies for government benefits, but the funds in the trust, under the direction of a trustee, can be used to supplement those benefits. Such an arrangement can provide a higher level of care, or for additional amenities, but whether and how such an arrangement would work depends on what state your child lives in. It is also somewhat risky in that future laws and regulations could negate your intentions, especially after you are gone and can no longer do anything about it.

It is always better, therefore, to *fully* fund your child's future, if you are able to, and not rely on qualifying for government benefits.

How do you provide for your child financially?

If you are not already a millionaire, it can be difficult, but it may not be impossible. The biggest problem is providing for when you are gone. The obvious way to do this is with life insurance, and there are a couple of possibilities that you should keep in mind:

- Many people buy life insurance when they are young or middle-aged. When you get to retirement age, the original purposes may no longer apply, but if you have a disabled child or other relative, you could just keep the insurance going, instead of canceling it or cashing it in. Since you bought it young, it is probably cheaper than if you bought the same amount of insurance today, especially if your health is not as good as it used to be. In fact, if there is enough cash value in the policy, you might even be able to stop paying premiums on it, and still keep it going.
- Another possibility, if you are married (or have someone else equally committed to your child's care): you can buy a "second-to-die" life insurance policy. Such policies cover two persons' lives, but pay off only when *both* have died. This is perfect, because it pays off just when you need it: when there is no longer a living parent or other financial provider. And because it is less likely to pay off as early as a policy on just one person, the premiums are lower, often a lot lower. And you can get these policies even if one of the two people covered is so unhealthy as to be uninsurable at all as an individual.

Life insurance, in fact, offers a number of possibilities, and you should talk with your agent about what makes the most sense in your situation. Among the points you should take into account.

- The life insurance benefits should go to the disabled child, but not directly, unless he or she is mentally competent and will not be relying on government benefits. In most cases, it is best to set up a "special needs trust" (see next section).
- You should also consider directing that the life insurance proceeds be paid out as an annuity, which guarantees a lifetime income for as long as she or he lives, no matter how long that is. This could be an inferior plan, however, if your child's disability (or other factors) make his or her life expectancy less than the average ó in which case, leaving the full proceeds to a trust is probably a better plan. It also reduces the discretion of the guardian and/or trustee ó which may be a good thing or a bad thing, depending on the circumstances.
- You should probably still be the owner of the policy during your own lifetime. This gives you the ability to cash in the policy, or borrow against it, in case your child's situation changes. You will also normally be the person to pay the insurance premiums for as long as you are alive, or perhaps not that long, depending on how the cash values in the policy grow.

There may also be other answers, besides life insurance. If you are a homeowner, for example, you probably want to keep your home for as long as you (and your spouse, if you have one) are alive, but after that, you don't need it. Your house, and other belongings, could be sold upon your death to provide for your disabled child. Or you may have financial assets whose earnings help cover your own expenses, but again, when you are gone, these could be willed to your child's trust. Some advisors suggest that retirement assets be set aside for the child. Or perhaps other family members want to contribute.

As with life insurance, these assets should usually be left in trust ó not just to impoverish your child so that she or he will qualify for government benefits, but because many disabled people are not able to take care of their own financial affairs. But it is generally

best to make arrangements that the trust not receive any funds until you yourself are gone, or incapacitated ó because tying up assets in a trust while you are still alive means that you may not have discretion to use them for the benefit of your child while you are still alive.

If the person in question is in fact your child, and if you have one or more other children, they should be part of your planning. First, one or more of them will be likely candidates to be the legal guardian (or helper, if a legal guardian is not required), and the more they know about your plans, the better they can carry out those responsibilities. Second, if they are being fully or partially disinherited in order to provide for the disabled child, the sooner they understand and buy into that, the better. The worst situation is for resentments to be stirred up and arrangements challenged just at the point when you are gone and your disabled child is most in need of family sympathy and support.

The Special Needs Trust

You may have been told that your disabled relative cannot have a trust and qualify for government benefits, and technically that is true. But the special needs trust is not an asset of the disabled person. And your disabled child may receive little or no income directly from the trust, but the trust may instead pay care providers or others for services that benefit your child.

This may sound complicated, and in fact, it can be. But the concept of a trust is simple: it is a legal arrangement whereby one or more competent persons (the òtrusteesö) provide for the welfare of someone else (the òbeneficiaryö). Trusts, like wills, can be drafted to contain any provisions that you like ó though, of course, an experienced attorney should be used to make sure that the trust document describes your intentions fully and accurately, that all contingencies are provided for, and that legal and tax technicalities are taken into account. In fact, you should find an attorney who *specializes* in working with special needs families, because there are many technical traps here, and many variations on the basic theme.

In order to meet federal Medicaid requirements, a special needs trust must be set up before the disabled person reaches age 65. If the funds in the trust come from the beneficiary ó for example, from a lawsuit or inheritance ó the trust must specify that any funds left over at the beneficiary's death are used first to repay government agencies that provided benefits during the person's lifetime. If the funds come from outside sources, such as from your own life insurance policy, your assets, or assets of other family members, then this payback provision does not have to be in there, and any leftover money can go to others in the family. If funds come from both kinds of sources, it is usually advisable to have two separate trusts, one with the payback provision, and one without.

A law firm, bank, trust company, or other corporate trustee is strongly recommended, and is often actually required. You may also, however, often have a family member who is co-trustee. Under a co-trustee arrangement, the family member may in fact make most of the decisions about expenditures for the disabled person, because the family member is more in touch with the day-to-day issues, but the corporate trustee oversees and must approve such decisions, to assure that the child's interests are protected.

If you can afford only to partially enrich your child, then what you need is a "supplementary" special needs trust. This document needs to be especially carefully constructed so as not to disqualify your child from receiving government benefits.

State laws are important, as they affect both taxation and coordination of government benefits. It is important that you work with an attorney who is familiar with the issues that pertain to your child's state of residence.

You will have to pay out of pocket to set up a special needs trust. Expect it to cost easily over \$1,000, and maybe a few thousand, depending on the complexity of your needs.

Guardianship

Not all disabled people require a guardian, but those with cognitive disabilities usually do, and those with physical disabilities sometimes do. It is best to establish guardianship, where required, before the child turns 18 and is a legal adult, because the legal procedures are less onerous. These vary from state to state, however, and your attorney can advise you how to proceed.

Who should be the guardian? Usually a parent fills this role, but provision has to be made for when no parent is around. A sibling of the disabled person is often the obvious next choice, but this can create a large burden for someone who is perhaps not best equipped to handle it, and it can also create financial conflicts of interest or other temptations. A sibling may still be the best choice, but the choice needs to be considered carefully.

One idea is to think of the adult disabled child's care-taking as a team effort. Members of the team might include the legal guardian who is responsible for personal issues, a corporate trustee who is principally responsible for handling major financial outlays and investment decisions, perhaps the executor of your will (who will represent your wishes), and case managers from the state agency and/or residential facility responsible for your child when you are gone. The more you can do to put this team in place while you are still around, the better established your child's future will be.

Next steps

There are four main steps to the process: creating a plan, drafting the right documents, funding the plan, and administering the plan over time.

Unless you have already started working with an attorney on these matters, we encourage you, as a next step, to go to the Special Needs Estate Planning Guidance System, sponsored by the National Alliance on Mental Illness. It is not a substitute for an attorney, but it presents an organized way for you to think through some of the issues raised here and apply them to your own situation. Then, when you do approach an attorney, you will understand what you need to do, and what the attorney is talking about. To try it, go to: http://www.nami.org/Template.cfm?Section=Special_Needs_Estate_Planning&Template=/ContentManagement/ContentDisplay.cfm&ContentID=8120.

If you are married, talk over these issues with your spouse before meeting with an attorney – many spouses are surprised to find that they have very different ideas about how their child should be provided for.

Finally, make sure that other people in your family understand whatever arrangements you set up. A well-meaning relative could leave money directly to your child and thereby disqualify him or her from receiving government benefits.

For More Information

- **Information on Special Needs Trusts:**
 - Richard W. Fee, "The Special Needs Trust", at kidsource.com (<http://www.kidsource.com/kidsource/content4/estate.dis.all.3.3.html>)
 - Barbara D. Jackins *et al*, *Legal Planning for Special Needs in Massachusetts*, People with Disabilities Press Series – an excellent source, with clearly written ideas and information, most of it applicable in all states (<http://www.disabilitiesbooks.com/index.php?act=viewProd&productId=1>).
 - The Special Needs Alliance provides an array of information, on its own site, and as links to other sites. They can also help you locate a special needs attorney in your area. (<http://www.specialneedsalliance.com/home>)
- **For more help:**
 - Planned Lifetime Assistance Network programs have been founded to assist families in planning for the future care of loved ones with lifelong disabilities. For more information, go to the National PLAN Alliance website, at: <http://www.nationalplanalliance.org/>.
 - SNAP (Special Needs Advocacy for Parents) offers advice and workshops on special needs planning. Go to: http://snapinfo.org/our_special.html.
 - The National Alliance on Mental Illness has a lawyer referral service. Go to: http://www.nami.org/Template.cfm?Section=Legal_Support&Template=/ContentManagement/ContentDisplay.cfm&ContentID=8109. The National Elder Law Foundation (<http://www.nelf.org/findcela.asp>) can also refer you to a Certified Elder Law Attorney, which would be a good place to start if the disabled adult in question is a parent or other senior citizen.
 - The National Multiple Sclerosis Society offers guidance for MS sufferers, much of it applicable to people with other disabling conditions (<http://www.nationalmssociety.org/living-with-multiple-sclerosis/index.aspx>).
 - For information about SSI and Medicare benefits, go to <http://www.ssa.gov>.
 - Contact your state agency dealing with disabilities for information about how Medicaid and other benefit programs apply in your area.