

Scenario

At age 17, Amy's student years are ending and her parents, Susan and Dave, are deeply concerned about Amy's future. Amy is a beautiful and loving child who has a severe learning disability and associated physical challenges. Her doctors believe that Amy will have a normal lifespan but will never function as an independent adult. Since Amy was born, Susan and Dave have dedicated themselves to meeting Amy's special needs. They have juggled middle class jobs, care giving, and frequent doctor visits. With Amy's approaching graduation, Susan and Dave recognize that they won't always have the energy to support and protect Amy.

Need for advocacy and money.

As long as Amy lives, she is going to need someone to watch out for her. Amy is simply incapable of maneuvering her own way through the medical bureaucracy to obtain proper care. As her parents age, Susan and Dave may require help themselves and become unable to ascertain and fight for the care Amy will need. Amy needs lifetime advocacy.

Amy's care is expensive and may become more so as time passes. Susan and Dave know that her quality of life will be greatly enhanced if she can receive more than government subsistence. The only way to do that is with family money. To last a lifetime, that money must be prudently invested, carefully budgeted, and protected from predators.

Government Benefits

Because Amy has a long life ahead of her and funds are limited, Susan and Dave will want to utilize government benefits to stretch their money. Otherwise, their limited funds could be eaten up with basic care in the early years and Amy will inevitably sink into poverty.

The most important government benefits will be Supplemental Security Income (SSI) and Medi-Cal. SSI can pay around \$800 per month, and Medi-Cal can provide medical care including nursing and intermediate facility stays. Eligibility rules are extremely complex, but they boil down to the simple fact that, without proper planning, Amy won't receive any government benefits until she has spent nearly all of her money. Medi-Cal benefits are often the most valuable, and a common way to qualify for them is to first qualify for SSI. SSI recipients are said to be "categorically eligible" to receive Medi-Cal .

Since Amy is unable to earn substantial wages, she can be eligible for SSI. However, Amy will be disqualified from SSI if she has more than \$2,000 in countable assets. If she receives more than \$20 of unearned income per month, her SSI benefits will be offset dollar for dollar. If she receives more than about \$65 of earned income per month, her SSI will be offset by 50% of that excess. Unearned income can be particularly problematic because it includes gifts and inheritances as well as most interest and dividends. Another trap is that providing Amy with food or shelter can partially offset her SSI benefits. If these offsets add up to her total SSI benefit amount, she will no longer be categorically eligible to

receive Medi-Cal benefits. So, if her family gives Amy countable assets or provides “in kind support” of food or shelter, their well intentioned gifts may cut off her medical benefits.

There is another way Amy may be disqualified from receiving SSI. Under a complex deeming formula, the government will look first to Amy’s parents to support their minor child. Because Susan and Dave earn a middle class income, Amy will be disqualified as long as she is a minor living at home. However, when Amy becomes an adult at 18, assuming she won’t be going to college, she can become eligible for SSI. If she is a full time student, the government may deem her parent’s income until she is 22.

Beyond the scope of this scenario, there are other ways to qualify for Medi-Cal benefits, but categorical linkage is often the most feasible way for children like Amy to qualify.

Exempt Property & Support

While income and investments will quickly disqualify Amy from receiving SSI and Medi-Cal benefits, many assets are exempt from being counted. Among these are a personal residence, one automobile, household items, personal effects, and items essential to self support. Thus, one strategy for qualifying for benefits is for Amy to use her excess cash to purchase exempt assets – such as a modified van or a residence. This is commonly called a “spend-down” strategy.

Some support will diminish Amy’s government benefits, but other support will not. To stretch their limited funds, Susan and Dave will want to avoid making gifts that would be counted as either income or in-kind support and maintenance. They will want to educate well intentioned grandparents and other family members. Cash and cash-equivalent gifts are counted as income. Under a complex set of rules, providing food or shelter is also considered income. However, Amy’s family can directly purchase exempt items such as furniture, clothing, theater tickets, and therapy sessions without reducing her government benefits. If they reimburse Amy for her purchase of the same items, that reimbursement would be counted as income. Thus, it is common practice to avoid cash gifts and reserve family money for direct purchases of exempt items and supplemental care that will enhance Amy’s life. However, there may be times when it will be in Amy’s best interest to sacrifice some government benefits to obtain something she really needs. Such trade-off decisions require an understanding of Amy’s particular situation as well evolving government rules.

Supporter Funded Trust

Susan and Dave can provide Amy with lifetime advocacy and otherwise enhance her life by creating a supporter funded trust for her benefit. Because none of Amy’s money is used to fund the trust, it is classified as a third party trust which is very flexible. Susan and Dave can participate in the management of Amy’s trust with the help of professional advisors for health care and asset management. As they age, they can shift more and more responsibility to a professional trustee. The trust can exist as long as Amy lives and then distribute any remaining assets to surviving family members or worthy causes.

While Susan and Dave are both alive, Amy's trust can be structured as part of their living trust and coordinated with its provisions to support themselves and any other children. Initially, Amy's trust may remain revocable so Susan and Dave can keep their options open. At some point in time, either at their deaths or earlier, Amy's trust will need to become irrevocable for her lifetime. The assets in Amy's irrevocable trust will be protected from creditors and predators by the trustee with optional oversight by other family members.

With sufficient assets, Amy's trust can significantly enhance her life. The trust can hire medical specialists and advocates to insure that she is not forgotten in a medical bureaucracy. A professional trustee will prevent accidental gifts that would cause Amy to lose her medical benefits. Throughout her life, Amy will enjoy a better life than can be had on \$800 a month, the SSI amount.

Funding by Supporters

Anyone other than Amy can contribute funds to Amy's trust or establish a parallel trust. However, if anyone makes the mistake of giving money to Amy or naming her as a beneficiary, that money should not be transferred to Amy's supporter funded trust. Money that becomes subject to Amy's control should normally be expended on exempt items or transferred to a beneficiary funded trust specifically authorized by federal statutes. A trust funded by the beneficiary is classified as a first party trust and is subject to substantial restrictions and recapture of benefit costs. Thus, Dave and Susan will encourage supporters to give to Amy's supporter trust rather than make direct gifts that would jeopardize her medical benefits or require the use of a restricted, first-party trust.

Suitable trust assets include all the asset classes that create a prudent portfolio designed to provide the lifetime payouts Amy will need. Susan and Dave may incorporate their investment preferences in the trust document. As Amy ages, income and liquidity will take precedence over growth and inflation protection. Where portfolio management costs are an issue, annuities can be used to assure a constant or market indexed cash flow over Amy's lifetime.

Life insurance is commonly used to inject cash at the death of a provider and facilitate tax efficient gifting strategies. Obviously, Amy should not be named as the beneficiary. If transfer taxes are not an issue, Amy's trust can be the beneficiary or the owner and beneficiary of insurance on the lives of family members. If transfer taxes are an issue, the family will want to use their annual gift tax exclusions to buy the insurance. Also, the family will want to make certain that insurance proceeds are not included in anyone's taxable estate. A typical life insurance trust will not work because it would grant annual withdrawal rights to Amy. For Amy, a withdrawal right will be counted as income and assets for SSI purposes. Under the tax code, withdrawal rights are essential to establishing a completed gift that qualifies for an annual exclusion. Thus, if transfer taxes are an issue, Amy's parents will consider creating an irrevocable trust which includes non-disabled beneficiaries who will be granted those withdrawal rights.

Normally, Amy's residence would not be placed in the trust due to the in-kind support rules. Susan and Dave can put rental property in the trust if Amy doesn't live in it without paying market rent back to the

trust. To avoid documenting market rents and the payment thereof, it would make more sense to buy a residence for Amy. In the month that the home was purchased or transferred, this in-kind support might cause her to temporarily lose benefits, but in subsequent months, her home would be an exempt asset with no further loss of benefits.

The trust rather than Amy should normally be named the beneficiary of family retirement plans and IRAs. Because Amy owns any retirement assets arising from her employment, her assets should go into a restricted first-party trust rather than the supporter funded trust. Even with a supporter funded trust, the tax implications of any retirement asset designations should be reviewed and updated regularly because distributions and beneficiary ageing materially change the tax picture. In particular, charitable beneficiaries provide both opportunities and challenges because they are tax exempt entities with infinite lives.

Don't Try This at Home

I wrote this scenario to provide parents and grandparents with a broad understanding of how they might prevent a child with disabilities from falling into poverty. Please understand that this scenario contains many simplifying assumptions. Without these assumptions, the scenario would become a legal treatise of considerable length and complexity. While necessary, these assumptions are landmines. Your plan can blow up if you step on some arcane rule (see the POMS at www.socialsecurity.gov to get a feel for the rules). For most families, professional advisors and a professional trustee will be essential to assuring the best possible future for a child with disabilities.

Results

If Susan and Dave do nothing, any money they leave Amy can be consumed by medical and facility costs that the government would otherwise provide. After her money is thus exhausted, Amy will become an impoverished ward of the state. By funding a properly designed trust, they can make the most efficient use of family resources to enhance Amy's entire life. Their trust can hire medical care advocates, provide supplemental care, purchase personal items, and pay for entertainment as long as Amy lives.