



# SPECIAL NEEDS PLANNING

## DEALING WITH THE FULL PICTURE

BY CALEB HARTY CFP®

What does “special needs planning” really mean? I often speak with people that believe that they’ve completed their special needs planning simply because they established a Special Needs Trust (SNT). Of course, SNTs are an extremely important component of planning for a loved one with special needs. When set up correctly, an SNT allows an individual to remain eligible for public benefits, while the trust owns a pool of assets that can be used to improve the individual’s quality of life. Unfortunately for most people, planning ends with the creation of the SNT. Of equal importance I would argue is the need to consider how much money should eventually fund the trust someday, which requires careful analysis and an in-depth understanding of the individual and family dynamic.

Having worked with numerous parents of special needs children, the common theme is that the parents simply want the best for their child. They make great sacrifices for their children, and often prioritize their children’s well-being over their own financial goals, such as saving for retirement. I try to frame the conversation so that parents think about what they want for their kids down the road, when they’re older and the parents have both passed on. Parents almost always want their children to maintain a lifestyle similar to what they provide for their children today. My job as a financial planner is to crystallize and define that.

For example, what type of housing do the parents eventually want for their child? Do they want to purchase a home, or have them someday live in their current home? If so, what types of supports will they need? Would they need or want someone to live with their child 24/7, or is someone checking in once a day or week sufficient? What will property taxes, maintenance, or condo fees cost?

If electronics are important to them, what will a new tablet or phone cost every year or two? If their sibling ends up on the other side of the country, what will a plane ticket cost each year to visit? How much should we build into the budget for meals and entertainment? On more of the business side of things, if

mom and dad aren’t around to advocate for and monitor the child’s affairs, what would it cost for a professional or community organization, like the ARC for example, to serve in that capacity? The trust may need to pay for investment management (hopefully the money is growing and being managed effectively), taxes (again, if the money in the SNT is growing, there would be taxes on the gains), possible accounting fees (a funded trust must file a tax return each year just like people do), and attorney fees (whether they are serving as trustee/co-trustee, or providing periodic consultation to ensure that the SNT is in compliance with evolving rules and regulations).

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Once we calculate these future costs, we would then factor in inflation (a dollar today is worth more than a dollar 20 to 25 years from now)—and the estimated life span of the child.

Fortunately there are public benefits available to offset the child’s future costs. Depending on the income, age of disability onset, etc., there may be SSI or SSDI, Section 8 housing vouchers, and Adult Family Care (AFC). Other benefits may be available, including funds from DDS for self-directed programs and other creative funding strategies. Further, ABLE accounts now allow an individual with needs to have a tax-free savings account (with certain restrictions), which does not count against their asset limits (generally \$2,000) to receive certain benefits.

In the end, looking at the budget of anticipated costs for the lifestyle the parents want for their child will be reduced by public benefits, but almost always not entirely. There will likely be a need for there to be funds available for their child, inside of the SNT, and a well thought out financial plan should take much of the randomness out of what that figure is and provide the parents with peace of mind that their child’s are met to the level they expect.

### ALL ABOUT ASSETS

After creating a plan which addresses the question of “How much money should I plan to leave my child?” the next step is to determine with what assets and when.

For starters, typically SNT’s are not funded until the parents’



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passing. This is because SNTs are complex and somewhat inflexible, and they create an administrative burden. Therefore, while the parents remain alive, it is often easier for them to provide for the child directly.

Many peoples' liquid assets are tied up in qualified retirement accounts such as IRAs or 401Ks. These are typically very inefficient assets to leave to a trust. Because these accounts have never been taxed, they will be fully taxable as ordinary income once withdrawals begin. Trusts pay taxes at the maximum federal rate (39.6%) on undistributed income above approximately \$12,000 (2016 figures). To put that in perspective, that's the same tax rate as a household making over \$466,000! Other taxes could also apply, such as state income taxes and the Medicare surtax (3.8%). These trust level taxes could normally be avoided by distributing the income to the individual, however, in a special needs context, these distributions could jeopardize public benefits.

Alternatively, Roth IRAs and life insurance death benefits are generally much more efficient assets to leave to a special

needs trust. Both are received income tax free, and therefore avoid many of the tax issues stated above. Estate planning attorneys and financial planners often recommend life insurance as a funding mechanism for an SNT. This life insurance would almost always be permanent, because the financial need is permanent, and term life insurance would likely expire before paying out.

To be more specific, the type of life insurance that I typically recommend is known as "second-to-die" or "survivorship" insurance, meaning that the policy's death benefit doesn't pay out until both parents/insureds have passed. This is generally universal life or whole life, which are both permanent in nature, but have some differences in how they operate. Whether to use a universal or whole life policy depends on the parents' goals. If the goal is to simply leave as much money as possible for the child's SNT, then universal life would be ideal, but if the parents want to create a significant cash value alongside the death benefit, for possible use/flexibility later, then whole life would be a better option.

Another benefit of life insurance is that it isn't tied to the stock market. Therefore, the SNT will receive the same amount, even if the parents pass away when the stock market has declined. Life insurance policies also generate "leverage," which means that the coverage is immediately in place, even though the premiums are quite small in comparison to the death benefit.

Having a legal and financial plan in place at one's passing is critical, so the foundation is best set today, because no one can predict what the future holds. Even if parents do not pass away prematurely, health changing is also a threat (and relatively, a more common scenario) that can cause rates to be unaffordable, or even worse rule it out altogether, for the above mentioned life insurance strategies. This is why while at least one parent is healthy now is a good time to lock in that good health and current age.

While thinking about all of this can be overwhelming for some, having the conversation and beginning to make a plan with the full picture in mind can be a rewarding process. This can provide the peace of mind and confidence that your child with special needs will have the life they deserve and that you desire for them. I hope this article proves helpful as you navigate ahead with that goal in mind. •

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#### **ABOUT THE AUTHOR:**

Caleb Harty CFP® is the Principal of Harty Financial. He specializes in helping parents plan financially for their children with disabilities as well as retirement planning. He lives in North Reading, MA along with his wife Amanda and can be reached at (978) 972-5961 or Caleb@hartyfinancial.com