



# Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 1

## A LITTLE BACKGROUND

### The Travel Trailer

Several years ago, probably fifteen to twenty, our family toyed with the idea of purchasing a small travel trailer to be used on those overnight trips to surrounding areas. Our reason was, because my son, Paul, was wheelchair bound and handicapped accessible lodging was not always available, it seemed to solve the problem of handicapped accessible lodging. One solution was a trailer called a toy hauler, a relatively small trailer with a drop down ramp to be used to load and unload a motorcycle, or other off-road vehicle. Although a great idea, the built-in ramp adds considerably to the overall length of the trailer and also to the cost. We liked the idea and were almost ready to leap. But the cost, we believed, was prohibitive. We just were not ready to take on an additional forty to fifty thousand dollar debt. So, we changed our search to used vehicles and whenever out and about, if I happened on a travel trailer for sale, I would stop and chat with the owner.

### A Startling Revelation

On one such occasion, I happened on a used travel trailer in a nice residential area. I stopped and visited with the owner and during our visit I told him of our plans, that we have a disabled son, and why we wanted to purchase our own take-along lodging. When I finished, he related the story of his brother who also had a disabled son. His brother and his brother's wife were both retired teachers and their son was a man in his middle twenties. As we spoke, I realized this gentleman was quite knowledgeable regarding disabilities and the accompanying family issues. But it was toward the end of our conversation that he let slip something that shocked me. We had been talking about planning for the future, what will happen to his brother's son when the father and mother are no longer alive or if they are alive, can no longer care for the disabled son. When I questioned him about who would care for the disabled son, where he would live, and so on, he told me that his brother had stated, repeatedly, that he doesn't care when he dies, that he doesn't care when his wife dies, that he doesn't care when his son dies. So long as his disabled son dies before he does.

What? Did I just hear what I think I did? How many people hope for that, for their child to die before they do? Could he be telling the truth? Well, the man I was chatting with assured me that his brother meant every word of what he said. I went home and worried about that conversation. I knew what I wished for Paul; to live a long life, to be happy, to make others happy. I knew that I, much the same as every one of my friends and acquaintances wished for their sons and daughters, wished for my son to outlive me by many years. But that conversation gnawed at me and although I had purchased a life insurance policy on myself several years earlier, I knew that the policy was nowhere near enough to care for my disabled son if he lived for an average lifespan. What I also now know is that since that time, every day, though I don't dwell on it, I think about it, what will happen when I'm no longer able to care for my son, because I'm no longer here or because I'm no longer physically able to do so.



## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 2

On numerous occasions, while discussing this topic with friends and acquaintances, many have told me, “Bob, we all think about that. My son is able bodied and has a master’s degree in finance and I still worry and think about that. I still worry about what will happen when I’m no longer able to be here for my son.” To those people, no offense intended, you have absolutely no idea and nothing I nor anyone else can say will help you understand. Until you’ve delivered a baby, you have no idea what it feels like to deliver a baby. Until you’ve raised a disabled child, you have no idea of the issues, emotions, and challenges of raising a disabled child and preparing for the future.

### **Not All Disabilities Are Equal**

Of course, there are varying levels of disability and varying levels of ability. For example, in any discussion of abilities and disabilities, Stephen Hawking must be mentioned. Stephen Hawking was diagnosed with ALS, a degenerative nerve disease that insidiously destroys the patient’s ability to walk, talk, feed himself, and eventually breathe. Stephen Hawking used an eye gaze communication device similar to the one my Paul uses. However, Stephen Hawking possessed one of the world’s brightest minds and while ALS destroys the nerves and the body, it does not destroy the brain. Thus, Stephen Hawking made his own decisions regarding his living arrangements, made sure his bills were paid, continued to work and teach, and lived a good deal longer than expected. He required physical help with toileting, bathing, transferring to bed and vehicle, and other assistance. But he was able, on his own, to hire caregivers to assist him. In reality, Stephen Hawking “needed” no one in the sense that my Paul “needs” someone. He could live on his own, of course assisted by his employees.

On the other end of the spectrum are disabled children or adults who cannot live on their own, who are unable to pay their own bills, who cannot decide on an apartment, who cannot feed themselves, etc., and unfortunately there are far more people in this group than there are Stephen Hawkings.

### **Severely disabled persons**

Parents of severely disabled children, of course depending on the level of disability, know that they, the parents, do things in the course of their day while caring for their child, that no one else will ever do for their child. Among those duties are transferring from bed to toileting chair, assistance with toileting if necessary, transferring from toileting chair to bath chair, transferring from bath chair to dressing area, shaving, feeding, either normally or via g-tube, etc. And some of these things occur many multiple times daily. And these parents wonder, “who will do these things for my child when I’m gone”?

Of course, in our society, there is federal, state, and local assistance for severely disabled people, so no one is “out on the street”. In El Paso, the State Center on Delta Drive is one such location. Funded by the state of Texas and the federal government, the center has many residents with varying degrees of disability. I’ve met quite a number of the residents on the Miracle League Baseball field. The center sponsors a team and employees drive the players to the field and then



## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 3

coach and “buddy” them. All in all, the employees I’ve met have seemed to be good and decent people who truly desire to help. Some years ago, however, the center experienced serious problems with certain employees. Allegations of sexual abuse were noted. The son of a prominent El Paso family died, I believe by drowning. So, if possible, an alternative is preferable

Depending on the family situation and our financial ability to pay, there is hope and there are several avenues available. My wife and I have looked at many and have semi-implemented a couple while others we know have implemented others.

**Supplemental Security Income (SSI)** is available through the Social Security Administration to any child under the age of 18 who meets the criteria, IF the child’s parents or guardians have limited income and/or resources. And, in the state of Texas, all SSI recipients also are automatically eligible for Texas Medicaid. Although Paul clearly met the criteria for disability, we (his parents) did not have limited income and/or resources. So, because his parents were not limited income nor limited resources, Paul was not eligible for SSI and thus, also not eligible for Texas Medicaid. The eligibility requirements for SSI are available at <https://www.ssa.gov/ssi/text-eligibility-ussi.htm>.

Thus, we carried Paul on my employer’s insurance plan and upon leaving that employer, on my TRS Care plan through Teacher Retirement System. I’ll add that parents must always be aware that employers do not exist to provide insurance or other benefits to employees. Insurance is expensive and the expense of insurance goes straight to the company’s bottom line. So, many if not most, companies tailor their insurance plans to fit the great majority of their employees. During my employment at a large firm, there were several changes to my employer’s plan due to a few of Paul’s rather expensive assistive devices, eg., wheelchairs, walkers, bath chairs, etc. From one year to the next, unannounced, the plan no longer covered durable medical equipment. Fortunately for us, TRS Care made no such changes although it was a constant battle over medication. The main battle, comical now but at the time infuriating, was the fight over Nexium. Paul was prescribed Nexium to counter acid indigestion which caused asthma. The Nexium was packaged in a packet that was dissolved in water and then injected into Paul’s g-tube. Of course, insurance would not pay for Nexium because there were generics. However, none of the generics were packaged in such a manner that the drug could be dissolved. Each was in a capsule with specific instructions; DO NOT OPEN CAPSULE AND DISSOLVE IN WATER. Only the Nexium brand could be so handled. So, every three months or so, the insurance company representative and I battled on the phone until the doctor’s special orders took care of it.

When Paul reached eighteen years of age, he became eligible for SSI on his own and because he owned no assets and had no income, he also became eligible for Texas Medicaid. In addition, his name finally bubbled to the top for the Texas Community Living Assistance & Support Services program (CLASS). “CLASS provides home- and community-based services to people with related conditions as a cost-effective alternative to placement in an intermediate care facility for individuals with an intellectual disability or a related condition. A related condition is a disability, other than an intellectual disability, that originated before age 22 and that affects a



## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 4

person's ability to function in daily life.” We now had a few new benefits, eg., up to ten thousand dollars for home improvements to make the home handicapped accessible, therapy, etc. But we also had some new problems. Paul's TRS insurance was his primary insurance with Medicaid supposedly picking up what TRS wouldn't. Again, we argued incessantly with TRSCare and now also with Medicaid.

In 2020 I applied for Social Security and began drawing an annuity in March. Unbeknownst to either my wife or I, and not mentioned by any of the CLASS people, when I retired and began receiving Social Security, Paul was, by law, no longer eligible for SSI and was moved over to SSDI and was enrolled under Medicare (<https://eligibility.com/social-security-disability>)

To date, we've noticed no downside to the conversion and in fact, the only upside was that I was able to drop Paul from TRSCare, thus saving \$500 per month. We contacted United Healthcare to speak to someone about a Medicare Advantage Plan for Paul and after some discussion, we enrolled Paul. The plan provided that whenever Paul needed medical care, Medicare was first in line and Medicaid was the supplement which picked up those costs not covered by Medicare.

All this is necessary and most appreciated. However, all this together does not answer the overriding question, “what will happen when I'm gone”. Paul will still require assistance with virtually every aspect of his life. And frankly, SSDI will not go far in providing those services. Paul will need a place to live (handicapped accessible) and he will need people, people who assist him in living. There are options in most families.

### **ABLE ACCOUNTS – Probably the Simplest Method to Provide**

**ABLE ACCOUNTS** “The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to create tax-advantaged savings programs for eligible people with disabilities (designated beneficiaries). Funds from these 529A ABLE accounts can help designated beneficiaries pay for qualified disability expenses. Distributions are tax-free if used for qualified disability expenses”.<sup>1</sup>

“The money in ABLE accounts can be used for qualified disability-related expenses, such as education, housing and transportation. Most importantly, ABLE accounts allow people with disabilities to save money without losing their eligibility for federally funded benefits such as Medicaid or Supplemental Security Income (SSI)”<sup>2</sup>.

ABLE accounts are available to 1) any individual whose disability occurred prior to the age of 26 which includes anyone who has cerebral palsy, autism, developmental delays, and a host of other disabilities and who 2) satisfies the Social Security's criteria regarding significant functional

<sup>1</sup> Internal Revenue Service ABLE Accounts – Tax Benefit for People with Disabilities  
<https://www.irs.gov/government-entities/federal-state-local-governments/able-accounts-tax-benefit-for-people-with-disabilities>

<sup>2</sup> NATIONAL DISABILITY INSTITUTE, ABLE ACCOUNTS  
<https://www.nationaldisabilityinstitute.org/financial-wellness/able-accounts/>



## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 5

limitations stemming from the disabling condition. Disability is defined under Social Security.<sup>3</sup> ABLÉ accounts may be managed by either the beneficiary (the disabled person) or by the beneficiary's parents, guardians, or other agent. Contributions to ABLÉ accounts cannot exceed the federal gift tax exclusion which is \$15,000 in 2021 and the total account should not exceed \$100,000. The primary downside of an ABLÉ account is, since the vast majority of disabled persons who may use an ABLÉ account are also eligible for Medicaid, the state Medicaid program may request payback from the ABLÉ upon the beneficiary's death. This is not a huge downside since in all likelihood, Medicaid has paid significant claims throughout the life of the beneficiary of the ABLÉ account.

Are ABLÉ accounts taxable. The short answer is, No. However, ABLÉ accounts are funded with "after tax dollars", money on which federal income tax has already been paid. ABLÉ account earnings are tax deferred which allows the balance to grow compounded. ABLÉ account withdrawals are tax-free when and if used for qualified disability expenses. Qualified disability expenses include education, housing, assistive technology, healthcare, etc.

### SPECIAL NEEDS TRUST

*"A special needs trust (SNT) is a trust that will preserve the beneficiary's eligibility for needs-based government benefits such as Medicaid and Supplemental Security Income (SSI). Because the beneficiary does not own the assets in the trust, he or she can remain eligible for benefit programs that have an asset limit. As a general rule the trustee will supplement the beneficiary's government benefits but not replace them. Examples of supplemental needs are costs for sitters, companions, and dental or medical expenses not covered by Medicare or Medicaid"*<sup>4</sup>.

An adequately funded Special Needs Trust is a popular method of preserving federal benefits while providing additional funds for those disability related expenses that cannot be satisfied through federal programs. A special needs trust may pay for medical costs that are not covered by Medicaid or Medicare, computers, telephones, family vacations, auto insurance, and more. And the purpose of the trust, and thus the job of the trustee, is to ensure that the assets of the trust are invested such that the trust will generate income net of costs such as trustee fees, accounting fees, etc., and will last through the beneficiary's lifetime. The ultimate goal is to spend the last dollar on the beneficiary on the last day of his/her life.

There are primarily two types of SNTs, 1) a first-party SNT, and 2) a third-party SNT.

**A first-party SNT** is funded with the assets belonging to the beneficiary. There are certain criteria that must be met in order for a first-party SNT to **not count** for SSI or Medicaid

<sup>3</sup> Social Security, Disability Evaluation Under Social Security  
<https://www.ssa.gov/disability/professionals/bluebook/general-info.htm>

<sup>4</sup> Special Needs Alliance.Org, "Your Special Needs Trust ("SNT") Defined  
<https://www.specialneedsalliance.org/the-voice/your-special-needs-trust-snt-defined-2/>





## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 6

purposes. 1) The beneficiary must be under 65 years of age at the time the trust is created and funded, 2) the trust must be irrevocable meaning that the beneficiary cannot change his mind and “undo” the trust, 3) the trust must include provisions such that, upon the death of the beneficiary, Medicaid will be reimbursed for any claims incurred after the creation of the trust, and 4) the trust terms must be such that the trust is administered for the sole benefit of the beneficiary. Funding of the trust may result from insurance settlements, in most cases as a result of some accident or other act that caused the disability. Many trusts created for cerebral palsy patients are funded by insurance settlements as a result of medical malpractice.

**A third-party SNT** is funded with assets not belonging to the beneficiary. The assets may be a result of a will provision, the beneficiary’s parents for example, whereby the parent’s assets, upon death of the last living parent, are transferred to the trust. Parents or grandparents may designate the trust as beneficiary of life insurance policies. With a third-party trust there is no obligation to pay back Medicaid. The creator of the trust, parents, guardians, or other agent decide how the trust remainder will be distributed upon the death of the beneficiary. Because many SNTs are created and administered for the benefit of a family member, at the same time designating a different family member, perhaps the trustee of the SNT, deciding how to distribute the trust estate upon the death of the beneficiary can be quite vexing and can cause rifts in families.

A third-party SNT (a trust funded with assets of someone other than the beneficiary, usually a parent, grandparent, life insurance proceeds, etc.), unlike a first-party SNT, may be revocable by the grantor. The grantor may revoke or modify the trust agreement at any time during his/her lifetime until the death of the beneficiary. A third-party SNT becomes irrevocable no later than the death of the grantor.

A third-party SNT may be created as a testamentary trust, that is, under the provisions of the will and testament of the grantor. Often, a testamentary trust is planned when the parents of a disabled child create their last wills such that upon the death of the last surviving parent, the third-party SNT is created and funded with the assets in the estate of the last deceased parent.

**MANAGEMENT OF A SPECIAL NEEDS TRUST.** An SNT is created for and exists to supplement the government entitlements received by the beneficiary. It does not replace those benefits. The beneficiary does not own the assets in the SNT. The beneficiary of an SNT cannot exercise control over any of the assets in the trust, cannot manage the assets, cannot name the trustee, cannot change the terms of the trust, and cannot make demands with regard to distributions. Thus, the SNT must provide for a trustee to make decisions regarding management of assets, distributions, etc.

The question of whom to select as trustee is a major decision. The trustee can be a trusted family member, a trusted friend, a professional trustee, a bank trust department, etc. The Most Important



## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 7

Job: Act Honestly.<sup>5</sup> This is known as the fiduciary duty which, under the U.S. legal system, describes a relationship between two parties that obligates one to act solely in the interest of the other.<sup>6</sup> This shouldn't have to be a requirement as it should just be part of every job. Your attorney should act in your best interests. Your doctor should act in your best interests. Your CPA should act in your best interests. Your financial advisor, your real estate agent, your insurance broker, your IT advisor, your mechanic, your partner in a partnership, your trustee, should all act in your best interests. Unfortunately, this is very often not the case. We are all human beings. We all have incentives that prompt us to behave in certain ways, sometimes unethically. We are all flawed.<sup>7</sup>

*A short anecdote. A prominent (at one time) CPA/Attorney in the El Paso area resigned from the practice of law in lieu of being disciplined by the State Bar Association. At the same time, his license to practice public accountancy was revoked. This attorney was the trustee of his wife's family's family trust. He acted NOT in good faith as trustee. Everyone is not cut out to be a trustee.* Appendix

*A second example of what can happen in a trustee relationship.*<sup>8 9</sup>

*A third, and perhaps best, example of what can happen in a trustee relationship.* Appendix

**The moral of the lesson is; *since it could very well be that your entire estate will wind up in the Special Needs Trust set up for your child, if you're going to put all your eggs in one basket, you'd better be damn careful about who you choose to carry the basket!***

**POOLED SPECIAL NEEDS TRUSTS.** A pooled SNT is a special needs trust established by non-profit organizations. The trust exists for two or more beneficiaries and each beneficiary's assets are accounted for in separate sub-accounts. Although each beneficiary's assets are accounted for separately, the assets are pooled in order to achieve economies of scale, lower costs to the trust, and higher returns on investments. Of course, each beneficiary's assets are only used for that beneficiary. Typically, pooled SNTs use professional trustees, e.g., bank trust departments. The ARC of Texas, and nearby The Arc of New Mexico, are non-profit organizations that, among their various duties, manage pooled special needs trusts. (The Arc of

<sup>5</sup> Nolo.com, Special Needs Trusts, The Trustee's Job.  
<https://www.nolo.com/legal-encyclopedia/special-needs-trusts-the-trustees-job.html>

<sup>6</sup> Investopedia.com What are Some Examples of Fiduciary Duty?  
<https://www.investopedia.com/ask/answers/042915/what-are-some-examples-fiduciary-duty.asp>

<sup>7</sup> "It's Not Easy to Act as a Trustee If You Want to do it Right: A Case Study"  
<https://www.linkedin.com/pulse/its-easy-act-trustee-you-want-do-right-short-case-study-bob-ramey>

<sup>8</sup> "It's Not Easy to Act as a Trustee If You Want to do it Right: A Case Study"  
<https://www.linkedin.com/pulse/its-easy-act-trustee-you-want-do-right-short-case-study-bob-ramey>

<sup>9</sup> "It's Not Easy to Act as a Trustee If You Want to do it Right: A Case Study (Spanish)"  
<https://www.linkedin.com/pulse/es-f%C3%A1cil-actuar-como-fideicomisario-si-quieres-hacerlo-bob-ramey>



## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 8

Texas, 8001 Centre Park Drive, Suite 100, Austin, TX 78754, 512-454-6694,  
[www.thearcoftexas.org/](http://www.thearcoftexas.org/)) (The ARC of New Mexico, 3655 Carlisle NE, Albuquerque, NM  
87110, 505-883-4630, [tsanchez@arcnm.org](mailto:tsanchez@arcnm.org), [www.arcnm.org/trustfund/](http://www.arcnm.org/trustfund/))

**DO I HAVE TO PAY THE TRUSTEE?** – Because a Special Needs Trust will likely be one of the most important parts of planning for the future and because management of a Special Needs Trust may be complicated and require very important skills, then yes, the trustee should be paid fairly. There are two primary methods of compensating the trustee, 1) a flat fee based on the value of the trust or, 2) an hourly rate. My own experience with a family trust was compensated at an hourly rate based on my CPA experience. Small SNT trustees may be compensated at a yearly rate.<sup>10</sup>

**IS A SPECIAL NEEDS TRUST A TAXABLE ENTITY?** – That's right! You heard me right! Yes, there is federal income tax involved if one has a special needs trust. If the trust is a first-party SNT it is typical for the financial institutions holding the trust's assets to send a 1099 to the beneficiary. The beneficiary then files a personal tax return including the income from the trust. Even in this situation, the SNT must file a federal Form 1041 with a Grantor Trust Information Letter attached.

Usually, a third-party SNT is funded by parents, grandparents, etc. This is the most common SNT, a trust set up by parents to care for a disabled child. The third-party SNT files a federal Form 1041, reports its own income and expenses, and provides the beneficiary a 1099 showing all income earned by the trust. If the trust DOES NOT distribute all income earned by the trust, then the trust itself may have a tax liability. If the trust distributes to the beneficiary all income earned by the trust, there is usually no tax liability to the trust itself.

**MAKING GIFTS TO SPECIAL NEEDS TRUSTS** – An individual, any individual, may make a gift to an SNT. If the individual's net worth is less than \$11.7 million, in 2021, then the individual may gift his/her entire estate to the trust. If the individual would like to make annual gifts, regardless of his/her net worth, he or she may gift \$16,000 in 2022 without worrying about a gift tax return.

**CAN I USE MY IRA, 401(k), RETIREMENT PLAN TO FUND MY CHILD'S SNT?** The answer is YES you can. In December 2021, only 32% of Americans held assets in a 401(k). However, assets totaled \$10.8 trillion held in IRAs. Consequently, these represent the largest share of wealth for most middle class Americans.

However, creating an SNT with tax deferred assets can be quite complicated. They include, when did the owner of the asset die, before the Required Beginning Date or after. Is there more than one beneficiary of the asset? Is the beneficiary a Designated Beneficiary or not? It is

<sup>10</sup> "How Trustees of Special Needs Trusts Are Compensated"  
Special Needs Answers, <https://specialneedsanswers.com/how-trustees-of-special-needs-trusts-are-compensated-15681>





## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 9

critical, before creating an SNT and designating beneficiaries, that the owner seek competent professional help from an attorney experienced with SNTs as well as tax deferred assets, a CPA experienced with SNTs, and a financial planner, again experienced with SNTs.<sup>11</sup>

The above information regarding Special Needs taxes is from the Special Needs Alliance.<sup>12</sup>

I highly recommend that the trustee engage a CPA experienced with trusts and SNTs in particular, to prepare the federal Form 1041 for the trust.

### **SKIP ALL THE MIDDLEMEN AND LEAVE YOUR ESTATE TO A SIBLING OF YOUR DISABLED CHILD SO THAT THE SIBLING MAY LOOK AFTER THE CHILD**

This is probably the approach favored by most middle-class parents. They would like to believe that because of the blood relationship, the healthy child will “do the right thing” always with regard to the disabled child, that the healthy child will welcome the disabled child into his home, make any necessary modifications, hire any necessary attendants, and “earn his place in heaven”. Although possible, the above scenario is quite unlikely. Just as one must be damn careful when choosing a trustee to carry his basket of eggs, so must one be just as careful, or more careful, when entrusting a healthy child with his inheritance to care for his disabled child. It can work. I know two individuals who are the primary caregivers for their disabled siblings and they both, the caregivers, are outstanding individuals. But how do we know how our healthy kids will behave as saints rather than as devils? Unfortunately, we don't know that.<sup>13</sup>

### **OK! SO WE'VE SET ASIDE SOME MONEY! BUT WHAT ABOUT LIVING ARRANGEMENTS? WHO'S GOING TO TAKE CARE OF MY SON?**

### **LEAVE IT UP TO THE STATE. THE STATE WILL TAKE CARE OF MY KID!**

If we do nothing, if we do no planning for living arrangements, if we make no arrangements for guardianship, if we leave no funds to care for our disabled child when we die, then the state will do it for us. In Texas, there are State Supported Living Centers for people with intellectual and developmental disabilities who are medically fragile or who have behavioral problems. One such center is in El Paso, Texas on Delta Avenue. “State supported living centers provide 24 hour residential services, comprehensive behavioral treatment services and health care services, including physician services, nursing services and dental services. Other services include skills training, occupational, physical and

<sup>11</sup> “Naming a Special Needs Trust as Beneficiary of Your IRA or Retirement Plan”

<https://www.specialneedsalliance.org/the-voice/naming-a-special-needs-trust-as-beneficiary-of-your-ira-or-retirement-plan/>

<sup>12</sup> “Filing a Tax Return for a Special Needs Trust: What a Trustee Needs to Know at Tax Time”

<https://www.specialneedsalliance.org/the-voice/filing-a-tax-return-for-a-special-needs-trustwhat-a-trustee-needs-to-know-at-tax-time/#:~:text=Trusts%20generally%20are%20considered%20separate,tax%20return%20for%20the%20trust.&text=The%20answer%20is%20that%20the,Grantor%20Trust%20Information%20Letter%E2%80%9D%20attached.>

<sup>13</sup> Beyond the Grave, Gerald M. Condon, Esq and Jeffrey L. Condon, Esq

Chapter 11, Protecting the Inheritance for the Disabled Child

Chapter 43, Can You Leave Your Child an Inheritance Without Disqualifying Him from SSI



# Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 10

speech therapies; vocational programs; and services to maintain connections between residents and their families and natural support systems.”<sup>14</sup>

## **LEAVE YOUR DISABLED CHILD IN THE CARE OF A SIBLING**

This option has already been semi-addressed above in the discussion regarding financial assistance and the same concerns are in play. If this is the choice, then the parents **MUST** discuss it with the healthy sibling. We can't just assume that the eldest son, the eldest daughter, the “best” sibling, will be amenable to this arrangement. If this is the chosen path, the healthy sibling may make room in his/her home and welcome the disabled sibling to live comfortably in his home. As stated above, I personally know two individuals who welcomed their disabled sibling into their homes and have made them welcome and part of the family. Of course, we must all remember that few of us live alone and there are others involved, spouses, children, etc. Caring for a disabled person can be a full-time job and disruptions in everyday life must be expected.

If the parents desire that the healthy sibling become the disabled sibling's guardian, and if the disabled sibling concurs (if cognitively capable of such a decision), and if the court concurs, then the healthy sibling is responsible for everything, from shelter, to food, to attendants, to medical, to SSI, to the everyday responsibilities of living. Moreover, depending on the extent of the disabilities, the responsibilities can be overwhelming.

Parents may choose to either leave their estate to the healthy sibling, taking the risk that the healthy sibling will resist the human temptation to act in his own best interests rather than those of the disabled sibling, or they might create a Special Needs Trust and appoint a trustee, a trusted friend or a professional, to manage the assets in the trust and provide funds to the healthy sibling as needed for those expenses not covered by SSI.

## **MICROBOARD**

A What? What on earth is a Microboard, some kind of medieval punishment tool? No, a Microboard is not a punishment tool. It is a valuable tool to not just provide for a disabled adult but is also a valuable tool to be used in preparing the disabled adult to achieve the most he/she is able.

“A microboard is a formalized “circle of support,” a non-profit corporation consisting of a small group of individuals who assist an individual with disabilities in creating and implementing a life plan. Participants are unpaid and maintain a personal relationship with the individual, who is also a board member, though non-voting, if a guardian has been named. In some states, microboards administer funds from Medicaid and other sources in order to hire and direct service providers.

---

<sup>14</sup> <https://www.hhs.texas.gov/services/disability/intellectual-or-developmental-disabilities-idd-long-term-care/state-supported-living-centers-sslcs>



## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 11

Hundreds of microboards exist in pockets across the U.S., although relatively few have been awarded guardianship status.”<sup>15</sup>

In Texas, a microboard is created, under state law, as a non-profit corporation. The corporation, like any other corporation, has bylaws which define the purpose of the corporation and is registered with the Secretary of State. The corporation will normally be designed to die upon the death of the disabled person. Because a Microboard is normally created for the sole purpose of caring for one individual, it is not tax-exempt as a public charity under IRC 501(c)(3). However, some microboard's bylaws specifically state that the corporation will serve the public, numerous individuals, usually up to some capacity. When the Microboard does actually begin to serve the public rather than simply one individual, the disabled son or daughter, then the Microboard should meet the criteria for tax-exempt status under IRC 501(c)(3). The Microboard may own property, in fact one board of which I am aware, owns the house in which the disabled person lives. The home was donated to the board by the parents of the disabled adult. Others may choose to place the home inside the Special Needs Trust and rent the home to the Microboard. The Microboard may hire personnel, contract with independent contractors, and legally sign government contracts. The Microboard may accept donations from individuals though donations are neither tax deductible for the individual nor tax-exempt to the Microboard unless the Microboard meets the legal criteria for tax exemption under IRC 501(c)(3) and has been granted such tax exemption. The Microboard may become a legal Medicaid Waiver provider and receive funds from state agencies for various purposes such as home remodel to accommodate disabilities and to hire personnel such as attendants or Day Hab. The Special Needs Trust may continue to provide funds, outside the Microboard, for those expenses not covered by SSI.

There are downsides. The Microboard must file federal income tax returns and, in Texas, Franchise Tax returns. One of the most obvious downsides is selecting and convincing individuals to become board members. Board members are not paid for their time on the board and many people are not willing to accept the sort of responsibility that comes with such a position nor devote the time required. Although, if COVID has taught us one thing, board meetings do not have to be face-to-face. If trusted friends and family members live out of town, a one hour zoom meeting every six weeks or so is ideal so long as nothing untoward occurs.

### **REFERENCES**

“What Happens to Adults with Developmental Disabilities When Their Parents Die? [The Cake Library](https://www.joincake.com/blog/what-happens-to-developmentally-disabled-adults-when-their-parents-die/) <https://www.joincake.com/blog/what-happens-to-developmentally-disabled-adults-when-their-parents-die/>

---

<sup>15</sup> “Microboards and Guardianship”, SPECIAL NEEDS ALLIANCE, <https://www.specialneedsalliance.org/blog/microboards-and-guardianship/>



Robert L. Ramey, P.C.  
Certified Public Accountant  
El Paso, TX 79925

Page 12

## Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

<https://generationlaw.com/2018/09/25/what-happens-to-special-needs-children-when-their-parents-die/>

“Who Will Take Care of my Disabled Child When I Die?” **RaniaCombsLaw PLLC**  
<https://raniacombslaw.com/resources/who-will-take-care-of-my-disabled-child-when-i-die>

“Preparing for a life after death: A guide for parents of adult children with special needs”, USA Today, Jan 22, 2018,  
<https://www.usatoday.com/story/money/2018/01/22/preparing-life-after-death-guide-parents-adult-children-special-needs/1046201001/>

<https://www.thestreet.com/personal-finance/what-happens-to-my-special-needs-child-after-i-die-13837726>

“[When Should You Consider a Pooled Trust?](https://www.specialneedsalliance.org/blog/when-should-you-consider-a-pooled-trust/)”,  
<https://www.specialneedsalliance.org/blog/when-should-you-consider-a-pooled-trust/>

“Developing an Estate Plan for Parents of Children with Disabilities: A 15-Step Approach”  
<https://www.specialneedsalliance.org/the-voice/developing-an-estate-plan-for-parents-of-children-with-disabilities-a-15step-approach-2/>



Robert L. Ramey, P.C.  
Certified Public Accountant  
El Paso, TX 79925

# Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 13

## APPENDIX

### Department of Justice Office of Public Affairs

FOR IMMEDIATE RELEASE  
Thursday, May 12, 2016

#### **Former Certified Public Accountant Sentenced to Prison for Tax Fraud**

A former certified public accountant in Georgia was sentenced to seven months in prison today after pleading guilty in February to one count of filing a false tax return, announced Acting Assistant Attorney General Caroline D. Ciruolo of the Justice Department's Tax Division and U.S. Attorney John A. Horn for the Northern District of Georgia.

According to court documents and information presented in court, Thomas D. Ziff was a licensed certified public accountant. From approximately January 2006 through December 2010, Ziff operated a tax return preparation and accounting business. During that time, Ziff was the trustee of a trust that was associated with the last will and testament of another individual. As the trustee of the trust, Ziff opened a bank account in the name of the trust at Wachovia Bank over which he had sole signatory authority. While serving as trustee of the trust, Ziff embezzled and caused to be transferred approximately \$300,000 from the trust bank account to other bank accounts that he controlled and used the funds for his personal use. Ziff failed to report the embezzled funds as income on his federal income tax returns for the years 2008, 2009 and 2010.

In addition to the prison term, U.S. District Judge Steve C. Jones of the Northern District of Georgia ordered Ziff to serve one year of supervised release and pay restitution to the Internal Revenue Service (IRS) in the amount of \$47,539.

Acting Assistant Attorney General Ciruolo and U.S. Attorney Horn commended special agents of IRS-Criminal Investigation, who investigated the case and Trial Attorney Christopher J. Maietta of the Tax Division and Assistant U.S. Attorney Steven D. Grimberg of the Northern District of Georgia, who prosecuted the case.

Additional information about the Tax Division's enforcement efforts can be found on the division's [website](#).

16-565  
Tax Division

**Topic:**  
Tax

*Updated May 12, 2016*





Robert L. Ramey, P.C.  
Certified Public Accountant  
El Paso, TX 79925

# Oh, Dear Lord! Who's Going to Care for My Disabled Son When I Die? And How Will They Do It?

March 23, 2022

Page 14

**Respondent:** Roy D. Salome (El Paso)

**Complaint No.:** 97-11-02L

**Certificate No.:** 010793

**Date of Board Ratification:** 5/14/98

**Disposition:** The respondent entered into an agreed consent order whereby his certificate was revoked in lieu of further disciplinary action. While acting as the executor, trustee, and accountant for an estate, the respondent misappropriated funds from the estate. The respondent violated *Section 21(c)(11)* of the *Act* and *Section 501.41(9)* (*Discreditable Acts*) of the *Rules*.



Robert L. Ramey, P.C.  
Certified Public Accountant  
El Paso, TX 79925

Page 15

**Oh, Dear Lord!  
Who's Going to Care for My  
Disabled Son When I Die?  
And How Will They Do  
It?**

March 23, 2022