Update on Special Needs Planning

2019

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I. INTRODUCTION

The cost of care for many persons with a disability can be prohibitive and is simply out of reach for most people to afford privately. Because many government-funded programs in the United States today provide substantial benefits, and in many cases are the only available programs for persons with disabilities, access to these services is critical. However, the requirements for qualifying for these benefits often thwart the efforts of families to provide support to their disabled loved ones. Special Needs Trusts, also called Supplemental Needs Trusts, are one of the building blocks for accessibility. These trusts are designed to provide assets for the care and comfort of disabled beneficiaries without jeopardizing their access to programs, funds and/or medical benefits that may be available to them. Additional programs, such as ABLE accounts, have been established by states in the past four years to enhance the lives of people with disabilities.

To qualify for the government benefits for disabled individuals a person must meet the definition of "disabled." A disabled person, according to the Social Security Administration, is a person who is over the age of 65, blind or unable to do any substantial gainful activity due to severe physical or mental impairments that will result in death or which have lasted for more than one year or will continue for not less than one year. 42 U.S.C. § 423(d) (l) (A). "Substantial gainful activity" is the ability to do work that produces earnings. "Physical or mental impairments" are disabilities that appear on the Social Security Administration Listing of Impairments. If drug addiction or alcoholism are contributing factors to the disability, and if the individual does not accept treatment for addiction, eligibility can be suspended. Social Security publishes the Program Operations Manual System to help its caseworkers determine disability.[1]

[1] The "POMS" are the rules described under the Program Operations Manual System, which are written to instruct Social Security caseworkers in the various offices throughout the United States. The POMS that are pertinent to the subject of this paper are found in the SI-Supplemental Security Income section. One can access the POMS pertaining to Supplemental Security Income at https://secure.ssa.gov/poms.nsf/home!readform. While the POMS do not carry the weight of regulations in the Tenth Federal Circuit (See *Ramey v. Reinertson*, 268 F.3d 955 (10th Circuit 2001)), they are very helpful and the most detailed policy guidelines that exist in the area of special needs trusts.

Once a disability is established, the type of benefit available will depend on additional criteria. Some programs, such as Social Security Disability Income ("SSDI"), base the benefit on the contributions to Social Security by the worker prior to her disability. With this benefit comes Medicare, which is a medical insurance program available to all workers who are disabled or to most people who have attained age 65. Receipt of SSDI and Medicare depends exclusively on disability or age and prior work history. There is no limit to unearned income or assets that can be owned by an SSDI or a Medicare recipient. In contrast, programs such as Supplemental Security Income ("SSI") and Medicaid are "means-based" programs, which measure the current income and assets of the disabled person to establish eligibility. In order to access these benefits, the recipient must not only be disabled, aged, sick and/or unable to work, but very, very poor. If additional assets become available to an SSI or Medicaid recipient, the benefits will be curtailed until those assets are used up. When the excess assets are gone, the disabled person can reapply for the benefits.

Government benefits for people with disabilities include cash payments and health care. SSI and SSDI provide cash for disabled individuals. For most recipients, this is the only monthly cash that they receive. The primary government health care programs are Medicare and Medicaid.

Medicare provides coverage for acute care, such as hospitalization and some limited rehabilitation. Under the Medicare law passed in 2003, prescriptions were covered beginning in 2006.[2] The Patient Protection and Affordable Care Act of 2010 ("ACA") increased the benefit of this prescription drug coverage by closing the gap for prescription drug costs called the doughnut hole.[3] Medicare recipients may also have access to private health insurance, which often pays for prescriptions and doctor visits. Medicare is administered directly by the federal government. Medicare does not exclude anyone with a pre-existing condition. However, Medicare does not cover the cost of long term custodial care. Long term care insurance will pay for custodial care but is not available for someone who already has a disability.

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[2] Medicare Prescription Drug, Improvement, and Modernization Act of 2003, www.medicare.gov. Medicare and Medicaid are administered by the Centers for Medicare and Medicaid Services ("CMS") under the United States Department of Health and Human Services.

[3] 42 U.S.C. § 1395w-114A.

Medicaid is the only government program in the United States that provides for long term skilled nursing care for disabled persons other than Veterans Affairs. Medicaid pays for prescriptions, therapy, and doctor visits, as well as custodial care. Medicaid, while a federal program, is administered by the states. Therefore, a Medicaid recipient who moves from one state to another state will have to reapply for Medicaid services in the new state of domicile. Regulations differ from one state to the next. In New Mexico, Medicaid, which is now called Centennial Care, provides funding for various programs, which include HMO services through private insurance companies and health care providers, institutional care in nursing homes and other facilities, financial assistance for the payment of Medicare premiums, Total Community Care, which provides home-based services for the elderly (available only in Bernalillo, Valencia and Sandoval counties), and the Developmentally Disabled Waiver ("DD Waiver"). As of 2016, Mi Via and Medically Fragile programs, which provide community-based services for disabled individuals of all ages, are also provided by Centennial Care providers.[4] In order to qualify for these benefits, a recipient must be disabled and must be essentially indigent. There is a limitation on the amount of income that a Medicaid recipient can receive each month ($2,313.00 in 2019), and the total amount of countable resources that a Medicaid recipient can have in any one month is $2,000. The resource amount has not changed since 1965.

Implementation of the Affordable Care Act has reduced the need for some of these government programs for some beneficiaries. For example, because health insurance companies are no longer able to deny coverage on the basis of a pre-existing condition, many people with disabilities whose needs are primarily medical, such as medications and therapy maintenance, can purchase health insurance and no longer need Medicaid for those services.

As a result of the ACA in New Mexico, Centennial Care is now offered to individuals and families whose household income is less than 138% of the Federal Poverty Level ("FPL"). The only thresholds for eligibility for this coverage are age, 19 through 64, and low income. The applicant does not have to be disabled and can own unlimited resources, which are not counted. This is called Medicaid Expansion under the ACA.

[4] Information about these services can be found at http://www.state.nm.us/hsd/mad.

In New Mexico in 2018, 840,486 people, or 40% of the population of New Mexico, were receiving services in one form or another under a Medicaid program.

The dilemma for families with family members with disabilities has always been how to provide a decent and meaningful lifestyle for their loved one, while at the same time guaranteeing access to crucial government benefits. Historically, families have tried various methods to protect the benefits for a disabled family member when additional assets may have been available that would cause disqualification. They might intentionally disinherit the loved one. They might attempt to create oral trusts or other arrangements with surviving family members. These methods have often had heart breaking and cruel results or can be ineffective or fraudulent. On the other hand, many relatives cannot bring themselves to disinherit a disabled beneficiary. As a result, the disabled beneficiary receives a gift or a share of an estate outright, and thus loses her government benefits until the gift or inheritance is used up. Planning with Special Needs Trusts can solve this dilemma.

An exasperating though common occurrence is a disabled child of a deceased or retired parent receiving automatically a lump sum payment from Social Security that is the accumulated SSDI benefit of the parent. The child is entitled to this benefit, which is a continuation of the parent's Social Security benefit. However, because Social Security may have taken two years to compute the benefit of the parent, it arrives as a lump sum that is far more than $2,000. The receipt of this payment, though received because the child is disabled, may cause ineligibility until the excess resource is used up. Planning with Special Needs Trusts can solve this dilemma.

Some disabilities are the result of someone else's negligence. In these cases, the disabled person may recover damages. However, the injured person may require lifetime assistance at enormous cost, which may be well beyond the amount of the recovery. Treatment of the effects of the injury necessitates government-provided benefits. Therefore, even though a recovery may provide substantial assets, the recovery itself can put access to these benefits at risk.[5] Planning with Special Needs Trusts can solve this dilemma.

[5] For more information about how to protect public benefits for disabled plaintiffs who recover damages throughout the United States, contact the Special Needs Alliance, www.specialneedsalliance.org .

II. HOW THE GOVERNMENT BENEFITS SYSTEMS WORK

A. The Basics

Planning for disabled beneficiaries requires a basic understanding of how government benefits systems work. These programs disburse benefits to millions of people in the United States every month. Yet, most people, and, unfortunately most professionals, do not have a grasp of the features and the distinctions among them. The names of the programs are very similar, which makes it more confusing. While access to the means-based programs requires special planning, it is important to know how other programs interrelate, and in some cases, complement the means-based programs. To help in that understanding, we have prepared two simple charts to illustrate and compare three programs provided through Social Security and to compare Medicaid and Medicare.

Comparison of Three Social Security Programs

SSI	SSA	SSDI
Supplemental Security Income	Social Security Retirement Benefit	Social Security Disability Income
Disability	Retirement	Disability
Cash + Medicaid	Cash	Cash + Medicare (After 2 years)
No work history	Work history	Work history
Income Cap - $771/month in 2019	Income Cap - $17,640/yr in 2019, if under age 66	Earned Income Cap - $1,220/month in 2019
Counts earned & unearned income	Counts earned income	Counts earned income
Resource cap $2000.00	No resource cap	No resource cap
Minimum cash benefit	Insurance	Insurance
Food and shelter	Unrestricted	Unrestricted
State supplements (Not NM)	Uniform in all states	Uniform in all states
US citizens only	All workers	All workers
May also have SSDI	May not have SSI or SSDI	May also have SSI
No dependent coverage	Covers dependents	Covers dependents
May have ABLE acct up to $15,000 per year		May have ABLE acct up to $15,000 per year

Comparison of Medicaid and Medicare

	Medicaid	Medicare
Program:	Health Care	Health Insurance A Hospital B Doctor Visits C HMO plans D Prescriptions
Administered by:	States	Federal
Eligibility:	Must qualify by income and resources	Entitlement by age or disability
Financial and Disability Qualifications:	ACA Expansion Income of Household Disability Services Income and Resources	Age **or** Disability
Covers:	Basic Medical Care Some in-home care programs; Skilled nursing care; Prescriptions	Hospitalization; Doctor visits; 100 days maximum rehabilitation; Prescriptions
Contribution:	Reimbursement required	Premiums and co-pay
Estate Recovery:	Yes	No

B. Means-Based Programs

In 1965, President Johnson signed the bills that created a health insurance program for retired Americans, Medicare, and a health care program for poor families, Medicaid. The bill was an amendment to the Social Security Act. It had originally been proposed by Harry Truman in 1945. In 1972, President Nixon signed the Social Security Amendments of 1972, which created the Supplemental Security Income ("SSI") system. Although the benefits under Medicaid and SSI are different, the rationales for the two systems are quite similar, and both find their statutory basis in the Social Security Act. SSI provides minimal cash payments each month that are designated to provide for food and shelter. In order to maintain eligibility for SSI, a recipient cannot receive income from any source in excess of $771.00 per month in 2019. Income, according to the SSI rules, is anything that "comes in" to the recipient in any month. At the end of the month, income that is not used up converts to a "resource." Thus, a resource can be accumulated income. An SSI recipient is not allowed to own resources that are available to be spent on food and shelter in excess of $2000.00. Income and resources are measured independently. The analysis for Medicaid eligibility is quite similar, although the income threshold is higher. In New Mexico, the income threshold in 2019 is $2,313.00 per month, for skilled nursing level of care services and some in-home services for disabled persons.

Some income and some resources are exempt from the eligibility calculations. Non-countable income includes other means-based payments such as food stamps, medical care and services, income tax refunds, loans, and any item that if retained would not be a countable resource. Exempt resources include the personal residence of the recipient; one vehicle, if it is needed to provide transportation to work, to medical services or is specially outfitted for the disability; household contents, such as computers, electronics, physical training equipment, hot tubs and ordinary furnishings for living; life insurance with a face value of less than $1,500.00 and irrevocable burial plans. Thus, a disabled adult who owns a $400,000 home,[6] a $60,000 specially outfitted van, whose life is insured by a $2 million term life insurance policy, and who has limited income, could qualify for SSI and/or Medicaid.

[6] The Deficit Reduction Act of 2005, signed by President Bush on February 8, 2006, requires that Medicaid eligibility shall be denied to applicants who have more than $500,000 in equity in their home. New Mexico has increased this figure to $585,000 in 2019.

Income and resources of family members can be deemed to a disabled family member under the SSI rules. This deeming concept is an odd one, but the rationale is that since SSI benefits are to provide food and shelter, if an SSI recipient is receiving some of those items from another source, then the ability of that source to provide those items is "deemed" to the SSI recipient, as if the SSI recipient were able to provide these services by herself. For example, in order to maintain SSI eligibility for a minor disabled child, a family which is supporting three children, one of whom is disabled, will be limited in the total amount of income that the family may earn each month, if it wants to protect the disabled child's benefits. A portion of the family's income will be deemed to belong to the SSI recipient. If the family earns too much income, the disabled minor child will not be eligible for SSI. There is a similar analysis for deeming resources.

But why is this significant? The government-provided cash benefit under SSI is paltry, a maximum of $771.00 per month in 2019. The amount of the SSI benefit is so small that maintaining SSI eligibility hardly seems to be a worthy goal. The prize that makes the quest worth pursuing is Medicaid. In many states, including New Mexico, eligibility for SSI categorically results in Medicaid eligibility. For many disabled individuals, such as disabled children, disabled adults who have no work history, and disabled adults whose work history does not provide an SSDI benefit at all, or one that is below $771.00 per month, SSI provides the gateway to the substantial medical benefits of Medicaid. As the charts demonstrate, no other government benefit besides Medicaid provides comprehensive, long term custodial and medical care. Therefore, observing the qualification criteria for SSI will enable a disabled beneficiary to receive medical care that she may not be able to obtain from any other source. If an individual is unable to qualify economically for SSI, she may be able to apply directly for Medicaid. The eligibility requirements for Medicaid are also means-based, requiring that the individual have minimal countable income and resources, but there are not the same deeming rules as there are with SSI.

C. Additional Related Programs and Legislation

1. Affordable Care Act (ACA)

The ACA provides that health insurance coverage cannot be denied to anyone with a pre-existing condition, beginning in 2014. Access to basic health insurance has allowed some

people with disabilities to opt out of the Medicaid system. Additionally, the ACA has expanded Medicaid health coverage to low income adults in New Mexico.

2. ABLE Accounts

In December 2014, Congress passed the Stephen Beck, Jr., Achieving a Better Life Experience Act ("ABLE"). The federal law amends Section 529 of the Internal Revenue Code as a new Section 529A. Only people whose disability was established prior to age 26 can open an ABLE account. Anyone can contribute to an ABLE account, but the total of all contributions in any one year cannot exceed $15,000, the federal annual gift tax exclusion amount in 2019. The funds in the account can grow income tax deferred, similar to an IRA or 529 plan. Distributions for the benefit of the disabled beneficiary can be made, income tax free, for education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight, monitoring, funeral and burial expenses, and other expenses approved by the US Secretary of the Treasury. Up to $100,000 in the ABLE account is excludable for SSI purposes. The beneficiary may direct the investments of the ABLE account, limited to twice a year. States must elect to participate in the ABLE program. There is a limit of one ABLE account per beneficiary. Medicaid, which is described as a creditor in the statute, gets paid back at the death of the beneficiary for any amounts paid by any state for the care of the beneficiary after the establishment of the ABLE account. Enabling legislation was passed by the 2016 session of the New Mexico Legislature, and was signed by the Governor on March 3, 2016. Many other states passed enabling legislation as of July 2015. The ABLE National Resource Center www.ablenrc.org keeps a chart of all of the states that have passed the legislation and updates on other states that are working on it.

3. New Mexico ABLE Accounts

In January 2018, the State Treasurer of New Mexico implemented an ABLE Account program. Named ABLE New Mexico, the program runs in partnership with the State of Ohio, called the STABLE program. One can access ABLE New Mexico at https://ablenewmexico.com and walk through the simple steps to open an account.

4. Disabled Military Child Act

On December 19, 2014, President Obama signed the Disabled Military Child Protection Act, which is Section 642 of the National Defense Authorization Act of 2015. This Act allows the disabled children of retired military personnel to have survivor benefits under military pensions directed to a Special Needs Trust for the child rather than to the child herself. A written statement designating the Special Needs Trust as the beneficiary should be sent to: Defense Finance and Accounting Services, Retired and Annuity Pay, PO Box 7130, London, KY 40742-7130. Guidelines were issued by the Department of Defense 2015, and can be found at http://www.moaa.org/uploadedFiles/Content/Take_Action/Top_Issues/Spouse_and_Family/SNTPolicyFinal31Dec15.pdf.

5. Tax Cuts and Jobs Act

The 2017 Tax Cuts and Jobs Act (TCJA) incorporated two pieces of legislation that will benefit people with disabilities. The TCJA incorporated the ABLE to Work Act, which allows beneficiaries of ABLE accounts who earn wages to direct those wages, up to the amount of the Federal Poverty Level in 2019 ($12,490 for an individual in 2019) to be deposited into his or her ABLE account. These deposits are in addition to the maximum $15,000 annual contribution limit. Therefore, an ABLE account of a working person with a disability could receive a total of $27,490 in 2019. It is still the case, however, that earned income will be counted for purposes of SSI and SSDI.

6. ABLE Financial Planning Act

The ABLE Financial Planning Act, also incorporated into the TCJA, provides that assets in a 529 plan account can be rolled over into an ABLE account, up to a maximum of $15,000 per year. The TCJA also provides that assets in a 529 plan can be used for qualified education expenses for children prior to graduation from high school rather than being restricted only to post-secondary education.

7. Changes to the New Mexico Probate Code Regarding Guardianships

The New Mexico Uniform Probate Code, Chapter 45, Article 5, provides a statutory system for protecting persons suffering from disabilities that render them legally incapacitated. Beginning in late 2016 and continuing throughout 2017, the New Mexico Supreme Court and

the New Mexico legislature undertook a thorough review of this system. The review was prompted in large part by a few vocal family members who felt excluded when guardianship/conservatorship proceedings were initiated on an emergency basis to protect an elder family member from neglect and/or financial exploitation. In 2017, the New Mexico Supreme Court appointed a commission to study the New Mexico system and recommend changes. The New Mexico Guardianship Study Commission (Commission) held its first meeting on April 28, 2017 and continued to meet through the autumn of 2017, issuing a final report and recommendations on December 28, 2017. During the Commission's tenure, two of New Mexico's most prominent non-profit fiduciaries, Desert States Life Management and Ayudando Guardians, Inc., were indicted by the New Mexico U. S. Attorney's Office for, among other things, crimes involving fraud against some of New Mexico's most vulnerable disabled citizens. The flagrant, harmful abuses by Desert States and Ayudando further damaged the credibility of the current system, which critics saw as encouraging abuses, and escalated the public outcry for change. Ironically, when change came it did not affect the procedure for emergency appointments of temporary guardians/conservators.

In 2018, and again in 2019, in response to the Commission's recommendations and the continued public outcry, the New Mexico legislature modified the old statutory system to add additional safeguards for persons alleged to be incapacitated. The New Mexico Supreme Court appointed an Ad Hoc Rules Making Committee to assist it in implementing the statutory changes by developing a set of new rules and mandatory forms. The changes include an emphasis on due process and greater transparency prior to the capacity hearing, more comprehensive notice provisions, the enumeration of specific rights afforded to the alleged incapacitated person prior to a judicial determination of legal incapacity, certification and bonding requirements for certain court-appointed fiduciaries, and more stringent reporting requirements for all court-appointed guardians and conservators. The term "interested person" has been expanded to include a host of individuals with a variety of connections to the person alleged to be incapacitated. All of these persons must be identified by the petitioner, in the petition and documents on a new case information sheet, which is submitted to the Court Clerk when the petition is filed. The identification of the interested person must include name, address and contact information.

While the new statutory scheme provides greater protections for New Mexico's most vulnerable adults, it also imposes greater procedural requirements, which may have the effect of making uncontested guardianship/conservatorship proceeding more expensive and cumbersome for ordinary people seeking to protect their loved ones. This would include most cases brought by parents of disabled children reaching the age of majority and family members filing petitions to protect an elderly parent or relative suffering from debilitating physical decline or progressive dementia.

In many respects the overall framework of a New Mexico adult guardianship/conservatorship proceeding remains the same as before the 2018 and 2019 changes to the law. A petitioner files a petition in State District Court in the county where the person alleged to be incapacitated lives. Once the petition has been filed, the assigned district court judge appoints three professionals, a qualified healthcare professional, a court visitor, and a guardian ad litem, to interview and evaluate the person, report to the Court on the nature and extent of the alleged incapacity, and offer recommendations. Under the new statute, the guardian ad litem is responsible for reviewing the content of the reports with the person alleged to be incapacitated. When the reports of the professionals have been filed, the Court holds a hearing to determine whether the person meets the legal definition of incapacity, and if so, who should be appointed as guardian and/or conservator to protect the person and the person's assets.

What has changed is that the capacity hearing is no longer sequestered. Anyone can stop by the courtroom while a capacity hearing is underway, go into the courtroom and listen to the testimony or the oral reports of the professionals. Even though the hearings are open, documents filed in the case are not accessible to the public and the reports of the professionals cannot be reviewed on-line. New provisions of the law place limitations on who is entitled to access pre-capacity hearing pleadings and review the reports of the professionals.

Under the new law, a petitioner is not required to be represented by a lawyer. A self-represented petitioner can look up the law and the rules on line and file a petition for the protection of a loved one. The petitioner, or the petitioner's lawyer, has sole responsibility for providing personal service of the petition and the new Notice of Hearing and Rights to the person alleged to be incapacitated. If service is not provided in accordance with the new rules, as established by an affidavit of service, the Court is not permitted to grant the petition. The

petitioner, or the petitioner's lawyer, is also required to provide a copy of the petition and the Notice of Hearing and Rights to persons identified in the petition as having an interest in the proceeding. The Notice of Hearing and Rights is more comprehensive than the standard Notice of Hearing and includes a recitation of the alleged incapacitated person's rights at the capacity hearing, which include the right to subpoena witnesses and present evidence, the right to examine witnesses including the guardian ad litem, the qualified healthcare professional and the court visitor, and the right to otherwise fully participate in the hearing.

The new provisions of the law place great emphasis on encouraging the autonomy and self-direction of the alleged incapacitated person and on identifying less restrictive alternatives to full guardianship/conservatorship. Petitioners are now required to advise the Court in the petition of what less restrictive alternatives have been attempted, the outcome of such efforts, and if none have been attempted the reasons why not. This means that greater care must be taken to gather information about the person alleged to be incapacitated before the petition is drafted.

After the hearing, if legal incapacity is established by clear and convincing evidence, the Court must issue one order appointing a guardian/conservator and issue a separate order specifying who is entitled to notice and access of information after a guardian/conservator has been appointed. Any appointed guardian and/or conservator is required to prepare detailed reports on mandatory forms. With very few exceptions, any appointed conservator will be required to post a bond, which will be calculated according to a formula designed to protect the assets of the person under protection. The State Auditor's Office will be randomly auditing the reports filed by conservators with the hope of identifying red flags that may suggest the mishandling of the protected person's funds.

After July 1, 2019, all professional guardians and conservators are required to be certified by a national or state organization recognized by the New Mexico Supreme Court as providing professional certifications for guardians and conservators. At present, we know the courts will accept certification by the National Guardianship Association. In the future, we hope that New Mexico will develop a state certification process that will provide professional certification for guardians and conservators.

Finally, the 2019 changes to the law provide for a formal grievance procedure whereby any interested person, including the person under protection, who believes a guardian,

conservator or representative payee is breaching a fiduciary duty or acting contrary to law or a Court's orders may file a grievance with the Court. The Court is required to review all grievances and take appropriate action. A mandatory form for use in grievance procedures is under consideration by the New Mexico Supreme Court. If approved, this form should expedite the review and resolution of grievances.

III. REQUIREMENTS OF SPECIAL NEEDS TRUSTS

A properly drafted Special Needs Trust preserves and shelters assets for the benefit of a disabled person so that she can obtain means-based benefits and have additional comforts, enjoyment, education, entertainment and medical care not otherwise provided by the government programs. A Special Needs Trust can hold an unlimited amount of funds and resources. In order for a Special Needs Trust to qualify as a non-countable resource, it must be written and its terms express. All distributions of income and/or principal must be in the discretion of the Trustee. The beneficiary cannot be given the power to demand income or principal. The Trustee must be prohibited from making any distribution that would jeopardize the recipient's benefits. The Special Needs Trust can delineate those items or categories for which distributions are proper. The language should never require distributions for health, support, food or shelter. The disabled individual must be the sole beneficiary of the trust during her lifetime. A Special Needs Trust must be irrevocable.

A. Third Party-Settled Trusts

The least problematic Special Needs Trust is the third party-settled trust which can be either an inter vivos irrevocable trust or a testamentary trust.[7] If the Special Needs Trust is a testamentary trust, it is settled law that it will not be counted as a resource for a disabled beneficiary.[8] A third party-settled Special Needs Trust can provide for a testamentary

[7] The POMS exclude third party trusts from special scrutiny. POMS SI 01120.200 D2.

[8] Transmittal 64, issued by Sally Richardson of the Health Care Financing Administration (now CMS) in November,1994, states that the definition of "trust" does not include a trust established by Will. Section 3259.1.A.1.

special power of appointment for the beneficiary, or can provide that the trust be distributed to the chosen remainder beneficiaries of the grantor at the death of the beneficiary. The corpus of a third party-settled Special Needs Trust can be preserved for future beneficiaries. In New Mexico, there is no need for independent review of a third party-settled Special Needs Trust by Medicaid.

B. Self-Settled Trusts

In 1993, Congress provided in 42 U.S.C. § 1396p(d)(3) that a person could not attain Medicaid eligibility by transferring her own assets to an inter vivos trust, even if the trust were irrevocable and the Medicaid applicant had no further control over the assets, for a period of five years following the date of the transfer. The Deficit Reduction Act of 2005 extended this five year look back period for trusts to all transfers of any sort. This "penalty period" can put the applicant in the worst possible situation, i.e., not having the assets to pay for care, but being penalized as if the applicant has the assets, and therefore, being unable to obtain Medicaid. The Deficit Reduction Act of 2005 mandates that the date of any transfer within the past five years will be deemed to be the date of the application for Medicaid, which means that the penalty period for a transfer begins on the date of application, not on the date of the transfer. Transferring one's own assets to a trust as a planning method five years in advance of need is only feasible when the disability can be planned for, such as with a Parkinson's patient or another chronic disease. For victims of accidents or disabling conditions from birth or with an unpredictable onset, this is not an option. For example, under SSI rules, a plaintiff in a personal injury suit is deemed to have constructive ownership of any recovery, even if the court establishes a Special Needs Trust. Because these assets are attributed to the plaintiff, if the plaintiff is disabled, the recovery would prevent eligibility for much needed means-based benefits. However, under 42 U.S.C. § 1396p (d)(4), two types of safe harbor trusts are described that can relieve this dilemma for SSI and Medicaid eligibility. Transfers of the disabled person's assets to these safe-harbor statutory self-settled trusts are exempt from the transfer penalty.

1. "(d)(4)(A) Trusts"

The first type of trust is provided for in 42 U.S.C. § 1396p(d)(4)(A) and is commonly called a "d4A" trust. Because the d4A trust is funded with the beneficiary's own assets, the statute requires that at the death of the beneficiary, the remaining assets in the trust must be

used initially to reimburse any state government that provided Medicaid to the beneficiary. Therefore, this trust is also often called a "payback trust."[9]

In addition to the payback requirement, the d4A trust must be irrevocable. According to the 1993 Act, it can be created only by a parent, grandparent, court or guardian. The disabled beneficiary must be younger than 65. New Mexico regulations state that funds of the beneficiary transferred to the trust after age 65may not be an exempt transfer. Anyone other than the disabled person can be the trustee of the trust. The trust can provide that after the beneficiary's death, once Medicaid is reimbursed, the remaining balance of the trust fund can be distributed to the intended beneficiaries of the disabled person.

The 1993 Act required that the beneficiary herself could not be the grantor, even though the assets being transferred to the trust are attributed to the beneficiary. This limitation on permissible grantors was cumbersome for 24 years. However, as a part of the 21st Century Cures Act, passed by Congress and signed in December 2016, the Special Needs Trust Fairness Act of 2015 was passed. This Act provides that the beneficiary is now an acceptable grantor of a self-settled special needs trust.

2. "(d)(4)(C) Trusts"

The second type of safe harbor for a self-settled trust is found in 42 U.S.C.§1396p(d)(4)(C).[10] In this case, if the disabled person transfers her own funds to a non-profit 501(c)(3) organization as Trustee, which manages the funds as part of a pooled trust for disabled persons, the transfer is exempt from penalty. The federal statute provides that the trust must be irrevocable; it can be created by the beneficiary as well as by a parent, grandparent, court or guardian; and the statute does not specify a maximum age of the beneficiary. The New Mexico regulations state that people over age 65 who fund a (d)(4)(C) trust may be subject to a transfer penalty. 8.281.510.11 D(1)(d)(iii). Furthermore, New Mexico regulations specify that the non-profit Trustee must notify the department in writing in

[9] 42 USC 1396p(d)(4)(A) states: **(4)** This subsection shall not apply to any of the following trusts: **(A)** A trust containing the assets of an individual under age 65 who is disabled (as defined in section 1382c (a)(3) of this title) and which is established for the benefit of such individual by a parent, grandparent, legal guardian of the individual, or a court if the State will receive all amounts remaining in the trust upon the death of such individual up to an amount equal to the total medical assistance paid on behalf of the individual under a State plan under this subchapter.

advance of any transactions involving transfers from the trust principal for less than fair market value. 8.281.510.11 D(2)(c). At the death of the beneficiary, the regulations state that "to the extent that any amounts remaining in the applicant/recipient's trust account upon his/her death are not retained by the trust, the trust pays to the department an amount equal to the total amount of Medicaid benefits paid on behalf of the applicant/recipient." 8.281.510.11 D(1)(d). What this means is that the non-profit organization maintaining the pooled trust can retain the trust balance at the death of the beneficiary and use the funds to help other disabled persons who might not have pooled trust accounts, and there is no payback to New Mexico. There are currently three pooled trusts in New Mexico. The ARCA Foundation is the Trustee of a pooled trust for the clients of ARCA and other people with developmental disabilities; CARC, Inc. serves as Trustee of a pooled trust to benefit its clients in Carlsbad; and The ARC of New Mexico serves as Trustee of a pooled trust that can benefit any disabled person who applies to open an account with them, in New Mexico or elsewhere. These pooled trusts have been approved by New Mexico Medicaid. The New Mexico Financial Institutions Division now requires that any non-profit serving as Trustee of a pooled trust must be licensed by that division.

[10] 42 USC 1396p(d)(4)(C) states: **(C)** A trust containing the assets of an individual who is disabled (as defined in section 1382c (a)(3) of this title) that meets the following conditions: **(i)** The trust is established and managed by a non-profit association. **(ii)** A separate account is maintained for each beneficiary of the trust, but, for purposes of investment and management of funds, the trust pools these accounts. **(iii)** Accounts in the trust are established solely for the benefit of individuals who are disabled (as defined in section 1382c (a)(3) of this title) by the parent, grandparent, or legal guardian of such individuals, by such individuals, or by a court. **(iv)** To the extent that amounts remaining in the beneficiary's account upon the death of the beneficiary are not retained by the trust, the trust pays to the State from such remaining amounts in the account an amount equal to the total amount of medical assistance paid on behalf of the beneficiary under the State plan under this subchapter.

IV. TRUSTEES OF SPECIAL NEEDS TRUSTS

Trustees of Special Needs Trusts have the same duties as Trustees of other trusts, which are to abide by the terms of the trust agreement in the best interest of the beneficiary, to not waste or squander the trust assets, to be loyal to the beneficiary above all others, and to exercise the level of care of a prudent person. However, Trustees of a Special Needs Trust have added responsibilities because of the disability of the beneficiary and the special conditions that apply to distributions from the trust.

A Trustee of a Special Needs Trust must develop a working knowledge of the government benefits for which the beneficiary is qualified, because the Trustee must understand which distributions are appropriate and which are not. This can mean not making certain distributions, such as cash to an SSI beneficiary, as well as making other distributions. A Special Needs Trust Trustee must know the long-term care plan for the beneficiary, her life expectancy, and what activities are possible or are reasonable to expect. A Trustee of a Special Needs Trust should be creative in anticipating activities or items that will enhance the beneficiary's life. For example, a beneficiary who is totally physically disabled, and who requires 24-hour care in a nursing home, but who is not totally mentally disabled, might enjoy a trip out of the facility even though it may require extra attendants and equipment.

A Special Needs Trust Trustee must understand which distributions would jeopardize the benefits being received. For example, SSI beneficiaries receive cash payments from the Social Security Administration that are deemed to be for the recipients' food and shelter. The receipt of any additional cash, or any item that would be "in-kind support and maintenance," will reduce the monthly SSI benefit up to a one-third reduction. Therefore, the Trustee should not pay the rent for the beneficiary who receives SSI without realizing that such a payment may reduce the monthly cash benefit, because that is an in-kind payment for shelter. This is not to say, however, that it might not be prudent for the Trustee to pay the rent, even though such payment will result in the reduction of the monthly benefit by one third, because the overall enhancement for the beneficiary might outweigh the reduction in cash. However, because ABLE accounts can be used to pay for housing, Trustees can distribute to an ABLE account, as long as the annual amount does not exceed $15,000, and the ABLE account can pay the housing expenses.

Although this is not the responsibility of the Trustee but of the beneficiary, the SSI program requires periodic reporting for all SSI recipients. Eligibility will be denied if the reports are not complete. The existence of the Special Needs Trust must be reported to the Social Security Administration and to Medicaid. Additionally, if the beneficiary changes her address, gets married, obtains more resources or more income, or is no longer disabled, these changes must be reported by the beneficiary to Social Security. The report is due within 10 days of the end of the month in which the change occurs. The beneficiary or her agent must respond promptly to any notices received from the Social Security Administration or from Medicaid. If notice is given of a change in benefits that is detrimental to the beneficiary, the beneficiary has 60 days in which to file a written notice of an appeal with Social Security in order to keep the benefits in place during the appeal process. The beneficiary cannot ignore or postpone dealing with the government agency.

Trustees of Special Needs Trusts should also know about other programs or services that might be available to the beneficiary for which the trust could provide or pay. For example, a Trustee should analyze whether purchasing health insurance is feasible or worth doing now that a person with a disability or a pre-existing condition cannot be denied health insurance; or whether to create an ABLE account; or whether the beneficiary could qualify for Medicaid expansion under the ACA, which does not have a resource restriction. The Trustee should continuously balance the well-being of the beneficiary with the extreme restrictions that come with government benefits, as well as the Medicaid payback at the end of the beneficiary's life.

As with many types of trusts, there is good reason to consider having co-Trustees of Special Needs Trusts. If the trust holds significant assets, a corporate Trustee may be beneficial for long term investment expertise. However, an appropriate family member could be a co-Trustee in order for the day-to-day needs of the beneficiary to be monitored. Trustees of Special Needs Trusts often need ongoing legal representation. To the extent possible, the Trustee should stay abreast of changes in the law. We recommend an annual review meeting with the Trustee and legal counsel.

IV. TAX ISSUES

A. Federal Gift Tax

Generally, gifts of any amount to third party-settled Special Needs Trusts with one beneficiary are taxable gifts. The $15,000 federal annual exclusion from gift tax rule does not apply to these transfers, because the use of the gift for the beneficiary is postponed into the future. In trusts, other than Special Needs Trusts, this problem is often addressed by the use of "Crummey powers." A notice is sent to a beneficiary by the Trustee giving her a right that exists for a limited time to withdraw the gift. The Crummey power converts the gift from a gift of a future interest to a gift of a present interest, thus making it eligible for the annual exclusion. But, because the beneficiary of a Special Needs Trust cannot be given the authority to demand withdrawal of any amount from the trust at any time, Crummey powers should not be given to her.

One way to solve this problem is to include other family members of the beneficiary as beneficiaries of the trust, with the limitation that if the disabled family member is receiving means-based government benefits, then the corpus of the trust is first to be used for the special needs of the disabled family member. This creates potential donees of the Crummey powers only for the purpose of transferring non-taxable gifts into the trust.

The third party-settled trust can be structured as a grantor trust, which keeps the transfers into the trust from being completed, and therefore, taxable gifts. The grantor is treated as the owner of the trust for income tax purposes. This can be accomplished in several ways. A simple method is to name the grantor as Trustee, so that she will retain the power to direct disposition and enjoyment of the trust. An additional method is to give the grantor a testamentary limited power of appointment over the trust, or for the grantor to retain a power to substitute assets in the trust.

Self-settled Special Needs Trusts are grantor trusts, because the beneficiary is deemed to be the grantor even though she may not be the formal grantor of the trust. Therefore, a transfer to a self-settled trust by the beneficiary is not a gift at all.

By statute, annual gifts to ABLE accounts are gifts of a present interest and are not taxable gifts.

B. Federal Estate Tax

A third party-settled Special Needs Trust will not be included in the federal taxable estate of the grantor if the third-party donor makes a completed gift to the trust. The third party-settled trust is not includable in the federal estate of the beneficiary, because the beneficiary does not have sufficient control over the trust fund to warrant estate inclusion, unless the beneficiary is given a general testamentary power of appointment over the trust. There is no reason why a third party-settled trust should not include generation skipping transfer tax exemption planning, especially if it is believed that there will be a large amount of corpus left over after the death of the beneficiary, which will pass to other family members and grandchildren.

The self-settled Special Needs Trust will be included in the beneficiary's federal taxable estate, because of the beneficiary's retained interest. However, the Medicaid payback provision may significantly reduce the value of the trust fund, if not eradicate it altogether. Furthermore, careful planning by the Trustee can result in distributions from the trust being sufficient to reduce the corpus to avoid federal estate tax as well as to reduce the Medicaid payback.

C. Fiduciary Income Tax

A third party-settled Special Needs Trust which is not a grantor trust should be assigned its own taxpayer identification number. It will file an income tax return for each calendar year, which is due on April 15 of the following year. While the Trustee is prohibited from distributing cash directly to the beneficiary, fiduciary income tax rules require that the Trustee report as distributable net income the value of all distributions from the trust up to the amount of the net taxable income of the trust for that year on the income tax return. For example, if the Trustee distributes funds for the purchase of a vehicle, which is titled in the beneficiary's name, this is an acceptable distribution of funds for an exempt resource. It will not disqualify the beneficiary from SSI or Medicaid as a distribution of income. However, to the extent that the trust had earnings, the distributable net income rules require that the Trustee report those earnings up to the amount distributed for the value of the vehicle as having been distributed to the beneficiary as income on a Schedule K-1. The beneficiary will report the income on her individual income tax returns, even though she did not receive the income in the form of cash. The Trustee can pay the cost of preparation of the income tax returns and can pay any income tax due directly to the taxing jurisdiction.

A Special Needs Trust is a complex trust, meaning that the Trustee has discretion to distribute income or principal. If a non-grantor trust retains income, the trust will be the taxpayer for that taxable income. A complex trust may take only a $100 exemption against its taxable income. The Internal Revenue Code provides an exception for some Special Needs Trust beneficiaries. 26 USCA section 642(b)(2)(C)(i),(ii). This statute was passed as a part of the Victims of Terrorism Tax Relief Act of January, 2002. It provides for a higher tax exemption if the trust is what is defined as a Qualified Disability Trust ("QDT"), that is, one that is a non-grantor trust and established solely for the benefit of an individual under 65 who is disabled. A trust is a QDT even if a remainder beneficiary is not disabled. For a trust that meets the definition of a QDT, the exemption that is allowed for the trust is the allowable personal exemption for the individual beneficiary. In 2018, the personal exemption was $4,150. The TCJA of 2017, while eliminating the personal exemption for individuals, retained this exemption through 2025 for QDTs.

In 2013, the Affordable Care Act added a 3.8% Medicare surtax on unearned income taxed at the 39.6% bracket. Therefore, non-grantor Special Needs Trusts with taxable income of more than $12,750 in 2019 will also be liable for the surtax. The American Taxpayer Relief Act of 2013 ("ATRA") increased the capital gain tax rate to 20% for trusts with income above $12,950 in 2019.

If a third party-settled trust is a grantor trust, it does not need to have a tax identification number different from the grantor's, and the income will be deemed to be distributed and taxable to the grantor. One advantage of a third party-settled Special Needs Trust being a grantor trust is that the grantor, who is often a close family member of the disabled beneficiary, can effectively give more to the beneficiary by paying the income taxes on the earnings of the trust.

Self-settled Special Needs Trusts are grantor trusts, and therefore, do not need to be assigned a separate taxpayer identification number, but use the Social Security number of the beneficiary. The income and expenses of the trust are reported on the beneficiary's individual income tax returns. In spite of this reality for income tax purposes, it is not uncommon for a different tax identification number to be assigned to a d(4)(A) trust, because the agencies providing the benefits may not understand that the trust is a separate entity from the beneficiary, and irrevocable, if it uses the Social Security number of the beneficiary.

V. CONCLUSION

In the United States today, a permanent total disability brings with it economic peril. A person who is born with autism, or who suffers from Alzheimer's, or who has a spinal injury, must address both the critical medical treatment required as well as the loss of economic self-sufficiency. Medical care is extraordinarily expensive and ongoing. Although the ACA and Medicare provide access to health insurance for disabled individuals, many disabilities necessitate special housing, transportation and education, which are not covered by health insurance. While many private charities provide worthwhile services, the enormous cost of caring for persons with permanent disabilities in this country is necessarily borne primarily by the government. However, maintaining eligibility for government programs often contradicts the efforts of family members to provide support and care for their loved ones. Special Needs Trusts and ABLE accounts can provide mechanisms for sheltering resources to benefit disabled family members so that these contradictory efforts can be harmonized. A well-managed support system using these types of accounts can maximize the use of government-provided services while supporting the family's care and enhancing the comfort and enjoyment of life for the disabled beneficiary.