Special Needs Trusts, Pooled Trusts, ABLE Tax Savings Accounts for Individuals with Disabilities: Where Do We Begin?

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Government Benefit Factors 101

One of the first questions an attorney needs to ask their client with special needs or their guardian when involved with a lump sum settlement or inheritance or some other form of back payment is, "Do they receive Supplemental Security Income (SSI) or do they receive Social Security Disability Insurance (SSDI)?"

The difference between each of these benefits is huge in clearly understanding what options they have in protecting a lump sum of assets. Whether considering the need to set up a Special Needs Trust or something else, perhaps an ABLE account. The amount of money involved will also play an important factor. A few hundred dollars will not be as important for the client's public benefits as a few thousand dollars will be in triggering problems for retaining their eligibility.

It is very important for the legal professional to clarify exactly what are the benefits your disabled client receives in order to provide the best advisement on their behalf. A rash decision to directly distribute a lump sum of money to the client or their guardian could immediately put at risk a client's public benefits.

Many people with disabilities solely rely on SSI and Medicaid for their monthly benefits. A client on SSI/Medicaid means they have very restrictive government benefits, means tested programs where additional income and assets discovered will jeopardize the future of these benefits.

Today, there are many planning options to choose from for your client, but it will depend on the type of government benefits they receive. It will also be relevant as to what amount of money they will be coming in receipt of and do they have capacity to handle this large financial responsibility. The type of disability from Developmental disability such as Down Syndrome or autism to Mental illness or to someone with a physical or medical disability may be important to factor in whether they are competent or not and whether a trustee is essential or not.

SSI and Medicaid Income have very strict asset rules when it comes to individuals with disabilities. The asset limit is a maximum of $2000 for individuals/$3000 for married couples. So there is very little room for savings each month. Any new found asset over $2000 will put their SSI/Medicaid benefits at risk.

SSDI and Medicare do not have any asset tests, but SSDI may change with any newfound earned income from wages. An annuity will not affect their SSDI. SSDI and Medicare benefits are not a means-tested programs. It is based on earnings paid into the Social Security system. So if your client is on SSDI and Medicare. These government entitlements will not be jeopardized by a large inheritance or settlement.

You may also need to be aware that some clients with disabilities who receive SSDI and Medicare benefits, may be receiving Medicaid or even SSI. Social Security calls these clients a Dual-Eligible candidates. So a person on SSDI/Medicare who receives Medicaid for long term care, in home care or a group home may require Medicaid to cover these important costs and thus they too are restricted in the amount of assets they receive, $2000. It is also possible your client could be receiving all four government benefits (SSDI, SSI, Medicare and Medicaid) in which you don't want to forget the first whether it's a means tested benefit program or not. The difference can be a malpractice claim.

What is a Special Needs Trust?
In order to understand the OBRA '93 Pooled Trust, one must first understand the purpose of a Special Needs Trust. A Special Needs Trust or Supplemental Needs Trust or SNT, as they're often referred to, is specifically designed to benefit a disabled beneficiary by providing for their special needs beyond the public benefits supplied by the government. Special needs defined are those needs that foster and maintain the beneficiary's health, safety and welfare, which are not provided for by any municipal, county, state or federal government.

SNTs assure that a disabled person receives a lifetime of adequate care and support that government benefits can offer. SNTs are generally not intended to pay for primary care costs nor "supplant" public benefits. They are intended to provide "supplemental" financial support to the beneficiary.

SNTs must be drafted in accordance with the OBRA 1993 Act, Social Security Administration (SSA) Procedure Operations Manual System ("the POMS") and state Medicaid and federal Centers for Medicare & Medicaid Services ("CMS") regulations. These trusts have a little magic in the language that makes them specialized trust instruments recognized under law. SNTs must be <u>irrevocable</u> to the beneficiary, whereby beneficiaries can never have any discretion over the trust, yet SNTs must give the trustee powers to terminate and amend, as these government agencies constantly change policies.

When a person with a disability is on public benefits such as Supplemental Security Income ("SSI") and Medicaid, a Special Needs Trust will provide a legal solution for an attorney serving an individual with disabilities and their family. The disabled beneficiary through the SNT, is getting a greater level of care utilizing the private assets in the trust, while maintaining public benefit eligibility, to protecting many essential services for the beneficiary's primary care needs.

How does a Special Needs Trust work?

Like a spendthrift trust, money from a SNT is not intended to be distributed directly to a beneficiary, but is used to pay providers for goods and services beyond what SSI and Medicaid can offer. The SNT is not intended to be used for basic food, rent or shelter-related utilities like heat, gas and electric and must specify that its intent is to "*Supplement, not supplant*".

If the SNT is properly drafted and meets the requirements of OBRA '93, the federal law, the Social Security POMS and Medicaid regulations, then the SNT's assets will be "non-countable" as an asset or resource, allowing the beneficiary to remain eligible or immediately qualify for public benefits.

The Special Needs Trust ensures a family that a legal, financial mechanism will protect the family's private interests and provide a lifetime of adequate care for a disabled loved one, while not jeopardizing their public benefits. The SSI benefits and Medicaid benefits received by a person with a disability (including services such as housing options and residential care, vocational services, day programs, in-home services, substance abuse and counseling, case management, co-payments for prescriptions and doctor co-payments and nursing care) are protected by the use of an SNT; a traditional estate plan or non-SNT will not protect from loss of those benefits.

Are there different types of Special Needs Trusts?
Yes, there are 2 basic kinds of SNTs:

Third party trusts and *self-settled trusts*

A *third party trust* is one that contains assets that belong to someone other than the disabled beneficiary. A classic example of a third party trust is one that is set up by a parent or grandparent in order to leave an inheritance to a disabled child or grandchild. Trust assets from a Third Party SNT are completely removed from Medicaid control or access.

A *self-settled trust* is a trust made up of the disabled beneficiary's own assets, also called a 1st party trust or self-funded trust or an OBRA '93 trust. For example, if a person with disability receives a personal injury settlement he/she might put the proceeds in a self-settled trust for his/her own use. A self-settled trust can also be funded with a person's own savings account, an IRA, inherited assets, Social Security back payment, a divorce settlement and even child support payments.

If a person puts assets in a self-settled trust in order to obtain SSI benefits, then the trust must meet certain distinct requirements under the OBRA '93 law, SSA POMS and the state Medicaid policies. Due to a wrinkle in the OBRA law, a parent, grandparent, legal guardian or a court, must create the trust. The trust must also contain a Medicaid "payback" provision for reimbursement to the state for medical assistance (POMS SI 011203B.1.h.[1]).

Is there more than one way to establish a Special Needs Trust?

Yes, there are really two ways.

Individual SNT Accounts- Many SNTs are set up as an individual 3rd party trust. There is also a self-settled version called the OBRA (d)(4)(A) trust. These individual accounts are typically managed by a family trustee and/or a corporate trustee or both as co-trustees. The individual trust accounts use their own separate EIN number.

Pooled Trust subaccounts- There are also pooled Special Needs Trusts that can be set up run by a nonprofit organization. Pooled trusts also referred to as a Self-Settled OBRA '93 (d)(4)(C) pooled trust; offer a beneficiary the option to set up their own account. Some nonprofits also offer a third party special needs pooled trust option for attorneys, families and individuals with disabilities. The pooled subaccounts share the same EIN for tax purposes.

History of the Pooled Trust

Many assume pooled trusts originated out of the 1993 OBRA federal law. Not true! The Ray Graham Association for People with Disabilities, a service provider that has served individuals with intellectual and developmental disabilities here in Illinois for over 60 years, had the vision to establish a pooled trust. The name of pooled trust program was called *The Self-Sufficiency Trust of Illinois*[2]. The Self-Sufficiency Trust of Illinois was first of its kind in the country. The Ray Graham Association put together a legislative package that ultimately passed the Illinois legislature in 1986. Several states soon followed

[1] Labeling a trust as a Medicaid payback trust, OBRA 1993 payback trust, established in accordance with 42 U.S.C. 1396p, is not sufficient to meet the requirements for this exception. The trust must contain language substantially similar to the language in POMS 1120.203b.1.h

[2] 20 ILCS 1705/21.1. The Self-Sufficiency Trust Fund, heretofore created under repealed Section 5-118 of the Mental Health and Developmental Disabilities Code.

Illinois to pass their own version of the Self Sufficiency trust program in South Dakota, Montana, and Alaska, which are all still in operation today.

In 1988, the ARC of Indiana established their own pooled trust called the ARC of Indiana Trust to allow families to provide for their loved ones. ARC-run organizations have been instrumental going back to the early 1990s in establishing pooled trust programs in many states across the country.

Most of these earlier programs established a “pooled trust” as a 3rd party pooled fund, in which there were no “payback” provisions. Once OBRA ‘93 became law of the land, these early pooled trusts had to reset their service model to add the new OBRA (d)(4)(C) self-settled version of a pooled trust to complement their earlier third party pooled trust services.

OBRA ‘93 Law (see addendum A)

An Omnibus Reconciliation Act allows Congress to establish a federal law with amendments, changes and additions to address the federal budget. Often Congress has attempted to balance the national budget in hopes of a presidential signature.

In the Omnibus Reconciliation Act of 1993 (OBRA ‘93), although the 103rd Congress’s main goal was on reconciling tax laws toward balancing the national budget, it added sweeping restrictions on trust laws in protecting assets for individuals seeking Public Aid eligibility. This stricter guidance on traditional trusts also included the addition of a three new trust exceptions.

The exceptions under Section 1396p d(4) of OBRA ’93 included the OBRA (d)(4)(A), an individual self-settled payback trust; a (d)(4)(B) self-settled (Miller trust, income protection trust), not used in Illinois; and a (d)(4)(C) pooled trust, as Medicaid qualified trusts. President Bill Clinton signed the Omnibus Reconciliation Act into federal law on August 10th, 1993.

OBRA (d)(4)(C) POOLED TRUST

A pooled trust is a combination of a 401K plan and a traditional special needs trust. Pooled trusts commingle the assets of multiple beneficiaries. Pooled funds, like mutual funds, are "unit trusts". This means that beneficiaries deposit funds into the trust in exchange for "units" of the fund, or simply a percentage of that pool, which reflects the beneficiary’s pro-rata share. The trust fund administrator will specify how the units are issued and redeemed, as well as handling the frequency of in and outflows, while overseeing the constant re-calibration of the pooled trust’s value on a daily/weekly basis.

Pooled funds can be either "closed" or "open". OBRA (d)(4)(C) pooled trusts are "open" pooled funds, which is the most common type of pooled account. This allows units to be redeemed at scheduled valuations, and accounts to be opened and closed at different times while allowing distributions to go out and deposits to come in as requested.

There are also "closed" pooled funds, which do not allow redemptions, except in specific circumstances or at termination of the trust. Closed pooled funds are usually established with illiquid assets, such as real estate, or set up as a hedge fund.

A nonprofit organization is required under OBRA ‘93 to have full authority and control over the pooled trust mechanism. It must maintain separate subaccounts for each client in which typically, monthly, quarterly and annual reports are made available for a beneficiary. The pooled trust is administered as "one" investment fund for management efficiency. The pooled trust earnings are shared amongst the beneficiaries, which provides a greater return on investment, particularly for the smaller trust accounts in a much larger pool.

Many nonprofits of pooled trusts are closely connected to larger local and national disability-related networks (e.g. The ARC, Ray Graham Association). Many nonprofits that run pooled trusts work closely with a bank agent or trust company to manage the financial aspects of the pooled fund. In some cases a bank or trust company may act as a Co-Trustee with the nonprofit, while other nonprofits of pooled trusts manage their own pooled funds, handling their own administration, investments and delivery of distributions through trust software.

Nonprofit organizations are typically run by a board of directors or trustees or other governing bodies. The pooled trusts organizations are no different. Pooled trust staff typically work daily with beneficiaries and the bank agents (Co-Trustees) in handling all requests, opening and closing accounts, expediting delivery of distributions, and tracking and reporting each beneficiary's trust account.

Pooled trusts can vary greatly in size and services, but most provide a litany of information about setting up a special needs pooled trust, finding a qualified attorney or trustee, and securing public benefits along with money management, housing, care planning, and trust distribution guidance.

42 U.S.C. 1396p (d)(4) TABLE 1

This subsection shall not apply to any of the following trusts:

(A) A trust containing assets of an individual under age 65 who is disabled as defined in section 1614 (a)(3)	***(C) a trust containing the assets of an individual who is disabled (as defined in section 1614(a)(3)) that meets the following criteria:***
	(i) the trust is established and managed by a nonprofit association
Which is established for the benefit of such individual by a parent, grandparent, legal guardian of the individual, or a court if	***(ii) A separate account is maintained for each beneficiary of the trust, but for purpose 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 1614(a)(3)) by the parent, grandparent, or legal guardian of such individuals, by such individuals or by a court
The state will receive all amount 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 title.	***(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 the state from which 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 title.***

(d)(4)(A) Individual vs. (d)(4)(C) Pooled Trust comparison

The individual (d)(4)(A) and pooled (d)(4)(C) share some common requirements under the OBRA ‘93:

Assets- The assets to fund OBRA ‘93 trusts in most cases should belong to the beneficiary. There can be an exception to where third party monies were transferred into an OBRA trust along with the beneficiary’s own self-titled assets. The Social Security Administration will still exclude the trust as an exempt “non-countable” trust and will re-classify the self-settled trust as a “Mixed trust”.

SSA allows the trustee, as long as they can account for the “mixed” assets (third party monies and self-settled assets), to remain without “payback” tied to the 3rd party monies, as long as they expend the third party monies first and then the self-funded assets last. This mixed trust should only be utilized under limited situations, e.g. under a small estate affidavit where the mixture of asset classes (self-settled/third party) for a disabled person makes sense to pouring into “one” OBRA account versus multiple trusts for cost savings and management efficiency. You should **never** pour a beneficiary’s own assets into a third party SNT, individual or pooled account.

Disability Criterion- Both OBRA ’93 trusts ((d)(4)(A), (d)(4)(C)) must be for a person who has a disability recognized by Social Security under section 1614(a)(3) of the Act, unlike Third party SNTs where there are no prerequisites of a beneficiary’s disability to establishing the trust.

There are also some key differences under the OBRA ‘93 statute between the individual payback trust and the self-settled pooled trust.

Payback- Both the (d)(4)(A) and (d)(4)(C) require a “payback’ provision written into the trust agreement stating that any medical assistance on behalf of the beneficiary that the state(s) provided must be paid back on death from the principle of an OBRA account. There should **never** be a “payback” provision on a third party trust.

Age- For now, under federal law there is no age restriction for pooled trusts. There is more to this story with age restrictions for beneficiaries 65 and older to discuss later. The OBRA (d)(4)(A) individual trust clearly defines an age limit. Under the OBRA law, a (d)(4)(A) must be for a disabled person under 65.

Investments- There is little guidance under OBRA ’93 on how the (d)(4)(A) should be managed as an individual self-settled trust. However, it is assumed that the (d)(4)(A) can be set up as an individual trust account with its own Employee Identification Number (EIN) with greater latitude on who the trustee can be and how the investments and trust shall be administered, as long as it’s in compliance with SSA POMS and state Medicaid regulations.

Unlike the self-settled (d)(4)(C), which is required under OBRA ‘93 to be managed by a nonprofit and the assets must be “pooled”. The nonprofit association is required to also maintain full authority and discretion over the trust management and investments, even if its board hires out an outside bank or investment advisor or Co-Trustee.

“Sole” benefit? - Both OBRA (d)(4)(A) and (d)(4)(C)s must provide clear language in their trust documents that the benefits from the trust must be for the “sole” benefit of the beneficiary. This is explicitly clear for (d)(4)(C), but not so clear for the (d)(4)(A); nonetheless, it is interpreted to apply that both self-settled trusts must be for the “sole” benefit of the beneficiary, no exception.

Sole Benefit for a Third party SNT?
A third party SNT can have tremendous latitude to allow a trustee to pay for gifts, or provide spending money to a beneficiary, or even assign more than one beneficiary to the trust without restriction or oversight from the Social Security Administration or Medicaid.

Who can establish the account? - The (d)(4)(A) and (d)(4)(C) can be established by a parent, grandparent, legal guardian, or the court for a beneficiary with a disability. One distinct difference for the (d)(4)(C) pooled trust is that Congress added that a legally competent, disabled adult can also establish their own pooled trust subaccount, which can include their durable Power of Attorney (POA-Property).

At the time of these written materials, there is Senate Bill 349 awaiting approval in Congress called the Special Needs Trust Fairness Act[3]. The intent of the bill is to remedy this disparity between the OBRA (d)(4)(A) and (d)(4)(C) trust sections. The legally competent disabled person or their POA-Property can only establish an OBRA (d)(4)(C) pooled trust from the OBRA '93 law. But the Special Needs Trust Fairness Act, if passed, will allow a legally competent individual or their POA-Property to set up their own self-settled individual (d)(4)(A) SNT equal to the (d)(4)(C).

Trustee- One of the other key differences between the (d)(4)(A) and the (d)(4)(C) is the (d)(4)(A) can be managed by a legally competent adult that could be a family member, attorney, bank or corporate trustee. A family member and a corporate trustee can even manage a (d)(4)(A) as co-trustees. The (d)(4)(C) pooled trust, under federal law, clearly must solely be under the discretion of the nonprofit association.

What is the deal with the "Payback"?
The OBRA '93 trusts clearly define specific language[4] to reimburse all states upon the death of the beneficiary for medical assistance that each state may have provided to a beneficiary. Under federal statute, the pooled (d)(4)(C) trust may also retain certain amounts remaining in the beneficiary's account on his/her death, before payback to the state Medicaid agency.

SSI has additional requirements regarding this payback provision clearly defined under the Social Security POMS section SI 01120.203B.3.a. Here are acceptable expenses for a trustee to pay from an OBRA trust before satisfying the state's payback lien:

- Taxes dues from the trust to the state(s) or Federal Government because of the death of the beneficiary;
- Reasonable fees.

POM SI 01120.203B lists prohibited expenses and payments from a Medicaid Special Needs and Medicaid pooled trust:

[3] Senate Bill 349 **(114th Congress): Special Needs Trust Fairness Act of 2015.**
[4] Labeling the trust as a **Medicaid pay-back trust, OBRA 1993 pay-back trust**, **trust established in accordance with 42 U.S.C. § 1396p**, or as an **MQT**, etc. is not sufficient to meet the requirements for this exception. The trust must contain language substantially similar to the language above. An oral trust cannot meet this requirement.

Upon the death of the trust beneficiary, the following expenses and payments are examples of some of the types not permitted prior to reimbursement of the State(s) for medical assistance:

- Taxes due from the estate of the beneficiary other than those arising from inclusion of the trust in the estate;
- Inheritance taxes due for residual beneficiaries;
- Payment of debts owed to third parties;
- Funeral expenses; and
- Payments to residual beneficiaries.

NOTE: For the purpose of prohibiting payments prior to reimbursement of medical assistance to the State(s), a pooled trust is not considered a residual beneficiary.

What is with the Pooled Trusts retained fees?
In contrast to an individual (d)(4)(A), a pooled special needs trust has unique authority to retain funds from a deceased beneficiary's subaccount, before payback to the state(s). Federal law and Social Security leave the retained amount up to the nonprofits. State Medicaid programs are not so friendly with this public policy.

States in recent years began to restrict, legally or illegally obstruct the pooled trusts' authority to retain funds. Many states have varied opinions with their Medicaid policies in allowing pooled trusts to retain any funds or a specific amount before "payback" to the state for medical assistance.

In a 2012 case in Pennsylvania, *Lewis vs. Alexander*[5] , a U.S. Court of Appeals for the Third Circuit affirmed a district court decision[6] that struck down a Pennsylvania statute that severely restricted the use of pooled special needs trusts. The court ruled in favor of the pooled trusts who had filed class action against the state of Pennsylvania's restrictive Medicaid policies. The Third Circuit court interpreted that the OBRA '93 federal law, allows pooled trusts the ability to retain funds on the death of a (d) (4) (C) beneficiary equal to 100% of the trust remainder value, before "payback" to any state has been made.

The nonprofit's primary mission in managing a pooled trust is to serve people with disabilities and their families as trustee. These retained funds authorized under OBRA '93 offered pooled trusts financial assistance to these often small, startup entities. These funds have allowed pooled trust organizations to grow and provide essential staffing, marketing needs and other resources to continue operations in perpetuity. It has also allowed many pooled trust organizations to achieve their mission statement of giving back to their disability communities in the form of charitable distributions or grants. Other pooled trusts will use the retained fees to extend the life of all their beneficiaries' pooled trust accounts, adding a larger dividend pay-in to each pooled subaccount. Under the 2012 SMART Act, Illinois has restricted OBRA pooled trusts' authority to retain any funds, until "payback" is fully satisfied to the state of Illinois for Medical costs.

The over 65 rule and its history

[5] *Lewis v. Alexander*, No. 11-3439 (3d Cir. 2012).
[6] *Lewis v. Alexander,* No. 06-3963 (E.D. Pa. 2011).

In 1993, Medicaid worked unsuccessfully through Congress to establish limits through the Omnibus Reconciliation Act. Their intent was to discourage the use of Medicaid-qualified trusts or any other financial mechanism for seniors in a spend-down toward finding immediate Medicaid eligibility for long-term care services.

In 1999, HR 3343, the Foster Care Independence Act[7] was enacted by Congress to add section 1613 to the Social Security Act. This imposed new transfer penalties on gifting and transfers in using an OBRA '93 trust under 42 U.S.C. 1396p (d)(4)(A) and 42 U.S.C. 1396 p (d)(4)(C), which could limit a senior from using a Medicaid Qualified Trust (OBRA '93 trust), by way of a transfer penalty, from qualifying for SSI /Medicaid benefits. The Foster Care Independence Act did little to persuade states to change their Medicaid policies on this issue. For a 65-year-old beneficiary on SSI, using an OBRA pooled trust, the Social Security Administration believe that beneficiary may be subject to a penalty loss of their SSI benefits for up to three years. The groundwork was laid for a future debate on this political policy issue.

Due to sweeping Medicaid reform changes under the Deficit Reduction Act of 2005 ("DRA")[8], the federal government set out to make changes to states' Medicaid policies, particularly in limiting use of OBRA pooled trusts for seniors. The DRA of 2005 was intended as a national law to provide states a cost-saving measure in preserving Medicare and Medicaid benefits for all. This established many new Medicare and Medicaid policies that included changes to the Medicaid lookback period from 3 years (36 months) to 5 years (60 months).

In 2008, Centers for Medicare and Medicaid ("CMS") sent out a national memorandum to all states. It clarified their interpretation for the OBRA pooled trust exception used by a person 65 or older, in which under the Foster Care Independence Act may cause a transfer penalty. CMS revised this interpretation in the letter for how the transfer of a senior's assets into an OBRA pooled trust should be reviewed. If the pooled trust met all the requirements under the OBRA federal law, CMS understood that it still would be an "exempt trust" under the normal Medicaid trust rules. Nevertheless, CMS built the argument that the assets going in to the trust would be for less than fair market value (FMV).

Here is the section of the letter stating CMS' argument:

Although a pooled trust may be established for beneficiaries of any age, funds placed in a pooled trust established for an individual age 65 or older may be subject to penalty as a transfer of assets for less than fair market value. When a person places funds in a trust, the person gives up ownership of those funds. Since the individual generally does not receive anything of comparable value in return, placing funds in a trust is usually a transfer for less than fair market value.

Typically under the Social Security Administration and Medicaid benefit criteria, a Fair Market Value transfer is an assessment that interprets fair market valuation of an asset in transfer as a gift to others or in exchange for something of equal value or a conversion to something like a trust. For a senior to

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[7] **P.L. 106-169: Foster Care Independence Act of 1999 SEC. 206. DISPOSAL OF RESOURCES FOR LESS THAN FAIR MARKET VALUE UNDER THE SSI PROGRAM.**

[8] **P.L. 109–171; 42 U.S.C. sec. 1305: Deficit Reduction Act of 2005 is a United States Act of Congress concerning the budget that became law in 2006; the act included a change in the Medicaid look-back period from 3 years to 5 years.**

provide an outright gift to another family member to simply impoverish themselves for benefit eligibility purposes is considered an egregious attempt to qualify for long-term care. A transfer penalty would incur under this circumstance based on a gift transfer that can easily be construed as a less than Fair Market Value exchange.

CMS' weak argument in this memo, that an aged person transferring their assets into an exempt OBRA pooled trust, a "sole benefit" trust mind you, somehow does not offer anything in comparative value in return for the beneficiary, is an inane one. However, what CMS set out to do with this memo in 2008 was to change the national trend running rampant on the use of the OBRA D4C pooled across the country for senior. This federal law was enacted back in 1993, to restrict the use of a specialized trust for seniors seeking long-term care. CMS' goal was to elicit a change in mentality at the states level, to ultimately change their Medicaid rules in disfavor of the pooled trust option for seniors and it worked. Today, over 20 states, including Illinois, do not allow such transfers to an OBRA (d)(4)(C) pooled trust for 65 and over individuals.

Following the 2008 memorandum from CMS, the Social Security Administration in 2009 issued revised POMS on the OBRA '93 (d)(4)(C) pooled trust, on whether a transfer from a beneficiary 65 and older into a pooled subaccount would incur a transfer penalty. In the revisions, SSA indicated in their POMS that a person over 65 joining a Pooled Trust <u>may incur a transfer penalty</u> for purposes of SSI eligibility. Therefore, Social Security was finally catching up to the 1999 Foster Care Independence Act, but was indifferent to what Medicaid was doing in restricting use of pooled trusts for seniors.

Illinois enacted its own changes to Medicaid policy pertaining to the Deficit Reduction Act of 2005 and OBRA '93 trusts (addendum B & C). After 7 years, Illinois reformed their regulations under the "Save Medicaid Access Resources Together Act[9]" (SMART Act 2012, see addendum B).

The Illinois SMART Act restricted OBRA '93 self-settled pooled trusts in Illinois from establishing subaccounts for beneficiaries 65 and older by way of a transfer penalty. It used CMS' argument in their 2008 letter that seniors' assets should be calculated differently than someone under 65, for less than Fair Market Value (FMV), thus making the exempt status of a pooled trust moot through the transfer when establishing a special needs trust account for a disabled senior seeking long term care Medicaid.

Along with this over-65 restriction, Illinois also added other draconian changes to their Medicaid policies. Illinois restricted a pooled trust's ability to retain any funds on the death of beneficiary as mentioned earlier, while strangely adding that a Public Guardian or a Guardian from the Office of State Guardianship could in effect create a pooled trust account for a ward over 65 without incurring the less than FMV transfer penalty.

In the 2012 *Lewis vs. Alexander* case, the Third Circuit also ruled in favor of the pooled trusts, holding there are no age restrictions written into the original OBRA '93 statute. Currently there is a case pending litigation cases here in Illinois on this over 65 restriction on using a pooled trust exception.

Distributions (See addendum D- Life's Plan Supplemental Distribution Guide)

After the SNT is set up, the work begins for the trustee when handling the distributions. Cash distributions are a big NO-NO! Any in-kind income support from the trust for an SSI recipient will result

[9] P.A. 97-0689.

in a 1/3 loss of SSI benefits. The legal interpretations are a bit of a minefield, but it is important for the trustee to get to know their beneficiary and their supports needs, but most importantly to know what government benefits they receive and how trust disbursements will affect those government programs.

Trust payments for rent, food and other household utilities are potentially risky and likely to cause a chunk of the beneficiary's SSI benefit to go away. Is it in the best interest of the beneficiary to lose 1/3 of their benefits? In some cases with larger trusts, it might be the right decision.

Finding ways as a trustee to make supplemental third party payments on behalf of a beneficiary can be challenging. Transactions cannot go directly through a beneficiary's own banking accounts without issues and potential dollar for dollar deductions of SSI benefits. Therefore, handling these transactions carefully through a guardian, a POA-Property or a personal agent or service provider of a beneficiary may be essential and best practice.

What happens when there are no personal agents to support a beneficiary? The trustee ultimately has to be careful with transactions and distributions, to not reduce the beneficiary's SSI benefits or risk loss of their key Medicaid health benefits.

Today, gifts cards by the Social Security Administration are considered a cash distribution--another big no-no! What if the beneficiary is not on SSI? Well, maybe a gift card is not such a bad idea after all…with limited use. Sometimes the trustee has to consider all the government rules that apply to determine best practice to either retaining all the benefits, or in some cases breaking the rules for the best interests of the beneficiary in the end. This would likely pertain to someone who might have a larger SNT wanting to buy or live in his or her own home and the need for payment in securing adequate, suitable housing. Each beneficiary has to be assessed by the trustee to serve their best interests, while minimizing risks or even a loss of their public benefits.

I have included a general list of allowable distributions from an SNT to better understand what a typical SNT can be expected to pay for without issue. (See Distribution Guide Addendum D)

What are the steps to setting up a pooled trust subaccount?

A pooled trust organization provides a trust document called a "joinder" or "transfer" agreement that a client or their legal representative signs into toward establishing a subaccount. Along with the trust agreement, usually other application and bank forms required completion before a pooled trust subaccount could be opened for a new client.

The pooled trust is established under a "Master" trust agreement by the nonprofit association. The "joinder" or "transfer" agreement is a skeleton version of the nonprofit's "master trust". The master trust typically is a more extensive document, not unlike a traditional trust agreement, covering all terms and conditions for establishment of the OBRA (d)(4)(C) pooled trust.

The "joinder" or "transfer" agreement is what allows the client, the disabled beneficiaries, to establish their own SNT. Some pooled trusts use their master trust as their joinder agreement. The transfer of a beneficiary's own assets to an existing pooled trust conveys ownership of their "countable" assets to the pooled trust. Once these assets are established within the pooled sub account, they are no longer countable for SSI/Medicaid eligibility purposes. It is as important to understand that as the transfer goes in to the trust as a countable asset as it converts into an exempt asset, the trust now considered a "Non-Countable Resource". The transfer has eliminated the requirements and need to complete a Medicaid spend-down with no further loss of SSI/Medicaid benefits moving forward. NOTE: the pooled assets may be "non-countable" as a financial mechanism, but the transfer of the assets may present a different story as mentioned.

Yes, pooled trusts do charge fees for their trust and trustee service for management. A representative from a pooled trust should be able to explain how to set up a pooled trust subaccount for your client easily. Fees can vary greatly between different pooled trusts. Fee costs may be charged as a flat rate or on basis points (bps) (100 bps=1%) based on the trust value, or a combination thereof. Be mindful that the fees for the mutual funds are typically <u>not</u> included in the pooled trust's fee schedule.

Many pooled trusts have lower minimums to establish trust accounts that could range anywhere from $10,000-$40,000. Today, banks and corporate trust companies set minimums anywhere from $300,000 to $500,000 or even much higher into the millions of dollars. Under federal and state law, there are no maximum dollar amounts or limit to what can fund a Special Needs trust.

In the last year, many of the "too big to fail" banks of the "2007 Great Recession" have discontinued trustee services for any Special Needs Trusts, no matter the size. Certainly, this will likely bode well for the pooled trust industry.

The Benefits of the Pooled Trust

Pooled (d)(4)(C) trusts offer attorneys, families, caregivers, and individuals with disabilities the ability to establish relatively inexpensive and effective trust accounts that provide supplemental funds to the beneficiary, while protecting any loss of government benefits.

Nonprofit Associations are required under statute to run and manage pooled trusts, "pooling" the funds of all the beneficiaries into "one" fund for management and investment purposes. This provides the ability to offer higher quality investments, particularly for smaller trust accounts with lower management costs. The mission of most special needs trusts is the same--to serve the supplemental needs of individuals with disabilities by improving their quality of life with private trust funds. The pooled trusts use their own trust documents to establish a subaccount within the pool. This also can save upfront legal costs in the drafting of a new trust agreement.

Though pooled trusts can vary greatly in size and experience, some pooled trusts play nicer with attorneys than others. Some pooled trusts have policies that either recommend or require that a potential trust client retain legal counsel before setting up a subaccount. Some pooled trusts work extremely well with attorneys, while others see the pooled trust option, as the alternative solution to using an attorney in the establishment of a special needs trust.

Some non-profits that run pooled trusts often provide families and attorney expertise in setting up a special needs trust account. Pooled Trusts often offer other added services beyond trust management. Added services can include: case management, advocacy, housing expertise and general social services to families and the beneficiary.

Pooled trusts can help individuals with disabilities and their families protect their financial choices. A pooled trust will allow an individual the opportunity to live independently with providing a wide array of supplemental goods and services to offset the beneficiary's own monthly living costs. Pooled trusts are ready to use entities particularly useful in crisis or during a Medicaid spend down. When a recipient may be on the clock in a Medicaid spend down because of an inheritance or unexpected windfall. A pooled trust account can be set up quickly, within days or weeks. The pooled trust can be a great way for an attorney, who does not practice in this specialty area of law, to effectively refer out cases to close while establishing a special needs trust account for their client with disabilities to a professional nonprofit organization.

Pooled trusts can be a considered as a contingent or successor trustee, particularly if the parents or family does not have a ready-drafted SNT. In some cases, the family trustee is a sibling who may pre-decease the beneficiary unexpectedly. Finding a qualified trustee for an SNT can be challenging, especially when there are no family members to serve in this capacity. Pooled Trusts are technically a corporate trustee run through a nonprofit. Some nonprofits also offer individual trust management services.

Pooled Trusts in your Community

Pooled trusts need collaborative partnerships and advisors to be successful, especially working with families, attorneys, service providers, trust companies, caregivers, guardians, and judges, but, most importantly, the individuals with disabilities themselves as their own advocates.

Pooled trusts can vary greatly, but most serve under a charitable purpose or a mission as trustee to serve in their communities, which is a service not always readily available in the financial industry.

Today, there are pooled trusts in every state, including several national pooled trust organizations available to serve individuals with disabilities and their families. The proliferation of pooled trusts has come, but may have slowed over the last few years due to the national trend of limiting use of these financial mechanisms for seniors.

The Stephen Beck, Jr. Achieving a Better Life Experience (ABLE) Act (Addendum E)

After nearly 10 years on the Senate floor in Washington, D.C., the Achieving a Better Life Experience ("ABLE") Act[10] was signed into law by President Obama on December 19, 2014. The original author of the ABLE bill, Congressman Ander Crenshaw, re-titled the Act, the "Stephen Beck Jr. ABLE Act" in honor of an instrumental Down syndrome advocate, who fought to see the ABLE bill through, but passed shortly before its passage. Beck, the father of a young daughter with Down syndrome, passed away at age 44, weeks before President Obama signed the ABLE bill into federal law. Illinois Governor Bruce Rauner signed Illinois Senate Bill 1383[11], the Illinois ABLE Act legislation, into law on July 27, 2015 and now as February 1, 2017 there is an Illinois ABLE tax savings program for individuals with disabilities and their families.

The ABLE Act creates a new option for <u>some</u> people with disabilities and their families to save for future planning, while protecting eligibility for public benefits. The ABLE Act allows, under the new Section 529A Qualified ABLE Programs, for an individual who is determined disabled before age 26, to set their own qualified savings accounts that receives preferred federal tax treatment.

[10] **P.A. 113-295** [**H.R. 647 (113th Congress)]: Stephen H. Beck Jr. Achievement for a Better Life Experience (ABLE) Act of 2013-2014.**

[11] **15 ILCS 505/16.6 - Illinois ABLE account program**

Even though the ABLE Act falls under the IRS 529 code, similar to 529 college savings plans, there is very little replication between the two 529 tax-free programs. There are but a few similarities with many more differences between a 529 college savings plans and a 529 ABLE Act tax savings account. The most common similarity they both share is that they get special IRS consideration as a tax-free account on earned interest. A 529-college plan is allowed to pay for college tuition and room and board. The ABLE accounts are accounts for people with disabilities that offer a wide, diverse list of qualified disability expenses. The ABLE account savings plan will get special privileges as a “non-countable” asset to meeting public benefit eligibility.

The ABLE accounts will improve the lives of individuals with disabilities who qualify and manage them successfully. Before the ABLE act, a person with a disability on means-tested public benefits was limited to no more than $2000 in assets/$3000 for a married couple. ABLE will provide a way for these individuals to save their own money or monies from family or others in an ABLE account for disability-related expenses. Final IRS regulations have been published on ABLE accounts. Today there are now more than 20 state run ABLE programs in operation. The Ohio STABLE program was first to launch an ABLE program. Tennessee, Nebraska and Florida have since followed with their own ABLE tax savings programs. All of these new ABLE programs are portable and open for business for ABLE beneficiaries across the country including Illinois residents.

Under the Illinois ABLE statute, the state’s Treasurer’s office has been appointed as the responsible party for the administration of the Illinois ABLE program. The Treasurer will work with the Illinois Investment Board to finalize details of the ABLE program, which will not happen until the final IRS regulations are published. As of February 1, 2017, Illinois opened the Illinois ABLE Program, see addendum under resources for website reference.

Contributions-
Contributions of no more than $15,000 per year, equal to the IRS maximum gift tax exclusion per person, are allowed into an ABLE account and distributions out of the savings account for Qualified Disability Expenses (QDEs) will be disregarded or given special exemption in determining eligibility for most federal means-tested benefits.

What are some of the important requirements of an ABLE account?

- An eligible individual may have only “**One”** ABLE account
- Designated beneficiary is the account owner (A parent or legal guardian may be allowed signature authority over the account)
- There is no longer a federal residency requirement related to establishing an ABLE account
- Total annual contributions (cumulative per year) may not exceed the federal gift tax contribution of $15,000 (this will be adjusted for inflation)
- Multiple individuals may make contributions to an ABLE account (any U.S. citizen can contribute)
- Aggregate contributions may not exceed the state limit for a 529 college savings account (Illinois- $350,000)

Who is eligible for an ABLE Account?

To be eligible, individuals must meet two requirements:

1. Age requirement: must be disabled before age 26

2. Severity of disability:
    - An individual applying for an ABLE account has been determined to meet the disability requirements for Supplemental Security Income (SSI) or Social Security disability benefits (SSDI) (Title XVI or Title II of the Social Security Act) and are receiving those benefits.
    - Person must submit a "disability certification" annually assuring the individual holds documentation of a physician's diagnosis and signature, and confirming that the individual meets the functional disability criteria in the ABLE Act (related to the severity of disability described in Title XVI of Title II of the Social Security Act).

What may funds from an ABLE account be used for?

- Distributions from an ABLE account may be made for "Qualified Disability Expenses".
- "Qualified Disability Expenses" are expenses that relate to the designated beneficiary's blindness or disability and are for the benefit of that designated beneficiary in maintaining or improving his or her health, independence, or quality of life.
- The term "Qualified Disability Expenses" QDEs should be broadly construed to permit the inclusion of basic living expenses and should not be limited to:
    - Expenses for items for which there is a medical necessity, or which provide no benefits to others in addition to the benefit to the eligible individual.

Qualified disability expenses include the following:

- 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 and monitoring
- Basic living expenses
- Funeral and burial expenses
- Any other expenses approved by the Secretary of the Treasury under regulations consistent with the purpose of the program

***Distributions for non-qualified disability expenses (non-QDEs) will be subject to possible 10% surtax and IRS income tax consequences and may affect eligibility for federal means-tested benefits.**

***Income**

Social Security will exclude contributions to an ABLE account from the income of the designated beneficiary. This will not exclude the original earned income by an SSI recipient from being countable at time of receipt. A distribution from an ABLE account is not income but is a conversion of a resource from one form to another, see SI 01110.600B.4.

Do not count distributions from an ABLE account as income of the designated beneficiary, regardless of whether the distributions are for non-housing QDEs, housing QDEs, or non-qualified expenses.

Other details about the ABLE Account

529 rollovers- As of 2018 529-college plans can be rolled over to a qualified ABLE account, but must maintain the current maximum contribution level of $15,000 per year.

Rollovers- an established ABLE account can be rolled over to another eligible ABLE recipient who is a designated family member as a sibling, stepsibling or half-blood sibling or by adoption. The rollover has to be to a designated family member who qualifies under the ABLE Act's disability criteria.

The ability for a family to rollover a 529 College savings plan to an ABLE account will not be a foregone conclusion as one might expect. The IRA will have to be worth less than $14,000 to make full transfer, it will depend on the 529 college plan termination policies, and there will certainly be tax consequences and termination costs.

How do ABLE account assets affect eligibility for federal benefits?

ABLE assets, if used for "qualified disability expenses," will be disregarded or receive favorable treatment when determining eligibility for most federal means-tested benefits:

- Supplemental Security Income (SSI): For SSI, only the first $100,000 aggregate in the ABLE account will be disregarded as a countable resource.
  - SSI payments (monthly case benefit) will be suspended if the beneficiary's account balance exceeds $100,000, but SSI benefits (eligibility) will not be terminated. Funds above $100,000 will be treated as a resource.
  - Housing expenses are intended to receive the same treatment as all housing costs paid by outside sources. However, new SSA instructions (POMS SI 001130.740) clearly define a housing QDE for the month it pays for rent or utilities of the home will be considered a countable resource and charge as dollar for dollar deductions for next month's SSI payment.
- Medicaid: ABLE assets are disregarded in determining Medicaid eligibility
  - Medicaid benefits are NOT suspended if the ABLE account balance exceeds the SSI countable resource threshold of $100,000, for Medicaid the maximum aggregate allowed here in Illinois for 529 college plan is $350,000, before loss of Medicaid benefits.
  - Medicaid Payback: Any assets remaining in the ABLE account when a beneficiary dies, subject to outstanding qualified disability expenses, must be used to reimburse a state for Medicaid payments made on behalf of the beneficiary after the creation of the ABLE account (the state of which the ABLE account retains Medicaid benefits is considered a creditor or lienholder of the ABLE account, not a beneficiary).

The Alternatives

Medicaid Spend Down

Medicaid spend down can be a nightmare for a person with a disability and their families, but in some cases it can be the attorney's best friend when the right size lump sum is available. Spending down can be a great alternative to setting up an SNT or even pursuing an ABLE Account option.

If a client has less than $20,000, the goal for a single individual is to spend down their lump sum asset to the allowable level of $2000 to meeting SSI/Medicaid eligibility requirements. The SSI/Medicaid asset limit is $2000 for individuals and $3000 for married couples. To protect your client, you want to be sure, they have the ability to document all allowable spend down items without issue. Here are some spend down items to consider:

- prepaying funeral expenses (see resources page)
- dental care, present and future
- paying off a mortgage or 3rd party debt owed on behalf of a person with a disability
- making repairs to a home (accessibility needs a plus)
- replacing an old automobile, accessible van
- paying for medical care, co-payments not covered under Medicaid
- updating home furnishings, bedroom furniture
- paying for home healthcare or case management
- buying a new home or new car (one car/one house in name of SSI/Medicaid recipient allowed)

The decision to spend down should be made carefully by an attorney, understanding their client's needs and public benefits. It's important to know your client's living arrangement, what is the amount of the assets they have come into, and how a spend-down will positively or negatively impact their benefits. Importantly, the attorney should be aware of the client's capacity to handle financial decisions. Are they competent in your eyes to handle a lump sum in a spend-down? Can the client keep adequate records or documentation for a potential audit? The client's level of independence will certainly predicate your decision to utilize a spend-down option for them. If there is guardianship, you will likely need to draft a petition to seek a spend-down plan over the use of an SNT or an ABLE Account for a judge's final approval.

Health Benefits for Workers with Disabilities

Health Benefits for Workers with Disabilities (HBWD) is Illinois' Medicaid Buy-In program that allows workers with disabilities the ability to purchase healthcare benefits through Medicaid. It allows individuals aged 16 to 64 to buy in to affordable healthcare coverage. You must be an employed resident of Illinois. It allows for a person with a disability to have access to Medicaid healthcare coverage with a higher income level and an IRA of any value. Once an individual becomes eligible for HBWD, they pay a monthly premium toward their healthcare coverage.

HBWD allows a larger increase in income of $3404 per month for an individual/$4588 per month for a couple. An individual can have up to $25,000 of assets in savings and a qualified IRA of any value managed by a corporate entity.

HBWD Covered Services:

- Hospital care
- Nursing facility care
- Doctor services
- Prescription drugs – up to four per month. (Prior approval is needed for more than four prescriptions in a month)
- Well-child care and immunizations
- Care at clinics
- Physical, occupational, and speech therapy
- Laboratory tests and X-rays
- Alcohol and substance abuse services
- Medical equipment, supplies, and appliances
- Transportation to medical providers
- Hospice care
- Home healthcare
- Renal dialysis
- Family planning
- Optometric care
- Podiatric care for diabetics
- Audiology services
- Mental health services

Eligibility for HBWD does not affect eligibility for Personal Care Assistants through the Department of Human Services home and community-based waivers. HBWD does not negatively impact eligibility for home health care attendants through the Department of Human Services. This program will not qualify an individual for long term care or community Medicaid for housing. This is less costly than Obamacare.

HBWD has a website with an online application here: http://www.hbwdillinois.com/abouthbwd.html.

An attorney can still choose disinheritance as a planning option. The Affordable Care Act (ACA) or Obamacare as media often refers offers disabled individuals the opportunity to purchase health insurance without the $2000 asset limit as long as the recipient does not need housing or long term care. ACA care is based on one's income or lack thereof and ability to find affordable health insurance through exchanges. As of these materials the future of the ACA is still unknown, likely to be repealed but with what?

A beneficiary can purchase exempts assets such as a condo, home or a vehicle. There are only but a few alternative trusts (discretionary, irrevocable income only trusts) and even fewer annuities (irrevocable Medicaid annuity), that can truly replace the effectiveness and value of establishing a Special Needs trust for a disabled client.

Attorneys today have many more planning options today at their disposal for a client with disabilities than ever before. Disinheritance is no longer necessary with the many types of Special Needs trusts available and now the advent of this new Illinois ABLE tax savings program. These new ABLE tax savings accounts will offer another tool in toolbox for the legal practitioner and trustees. A qualified ABLE account candidate will be able to save more of the monthly income and protect small amounts of their private assets for long-term use without loss of key government benefits.

OBRA 1993- The Federal Statute Addendum A

Sec. 1917. [42 U.S.C. 1396p] (a)(1)

(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 1614(a)(3)) 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 title.
(B) A trust established in a State for the benefit of an individual if—

(i) the trust is composed only of pension, Social Security, and other income to the individual (and accumulated income in the trust),
(ii) 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 title, and
(iii) the State makes medical assistance available to individuals described in section 1902(a)(10)(A)(ii)(V), but does not make such assistance available to individuals for nursing facility services under section 1902(a)(10)(C).

(C) A trust containing the assets of an individual who is disabled (as defined in section 1614(a)(3)) that meets the following conditions:

(i) The trust is established and managed by a nonprofit 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 1614(a)(3)) 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 title.

(5) The State agency shall establish procedures (in accordance with standards specified by the Secretary) under which the agency waives the application of this subsection with respect to an individual if the individual establishes that such application would work an undue hardship on the individual as determined on the basis of criteria established by the Secretary.

(6) The term “trust” includes any legal instrument or device that is similar to a trust but includes an annuity only to such extent and in such manner as the Secretary specifies.

(e)(1) In order to meet the requirements of this section for purposes of section 1902(a)(18), a State shall require, as a condition for the provision of medical assistance for services described in subsection (c)(1)(C)(i) (relating to long-term care services) for an individual, the application of the individual for such assistance (including any recertification of eligibility for such assistance) shall disclose a description of any interest the individual or community spouse has in an annuity (or similar financial instrument, as may be specified by the Secretary), regardless of whether the annuity is irrevocable or is treated as an asset. Such application or recertification form shall include a statement that under paragraph (2) the State becomes a remainder beneficiary under such an annuity or similar financial instrument by virtue of the provision of such medical assistance.

Sec. 1614. [42 U.S.C. 1382c] (a)(1)
For purposes of this title, the term “aged, blind, or disabled individual” means an individual who—

(A) is 65 years of age or older, is blind (as determined under paragraph (2)), or is disabled (as determined under paragraph (3)), and
(B)(i) is a resident of the United States, and is either (I) a citizen or (II) an alien lawfully admitted for permanent residence or otherwise permanently residing in the United States under color of law (including any alien who is lawfully present in the United States as a result of the application of the provisions of section 212(d)(5) of the Immigration and Nationality Act [42]), or

(ii) is a child who is a citizen of the United States, and who is living with a parent of the child who is a member of the Armed Forces of the United States assigned to permanent duty ashore outside the United States

(3)(A) Except as provided in subparagraph (C), an individual shall be considered to be disabled for purposes of this title if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months.

(B) For purposes of subparagraph (A), an individual shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work. For purposes of the preceding sentence (with respect to any individual), “work which exists in the national economy” means work which exists in significant numbers either in the region where such individual lives or in several regions of the country.
(C)(i) An individual under the age of 18 shall be considered disabled for the purposes of this title if that individual has a medically determinable physical or mental impairment, which results in

marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

(ii) Notwithstanding clause (i), no individual under the age of 18 who engages in substantial gainful activity (determined in accordance with regulations prescribed pursuant to subparagraph (E)) may be considered to be disabled.

(D) For purposes of this paragraph, a physical or mental impairment is an impairment that results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques.

(E) The Commissioner of Social Security shall by regulations prescribe the criteria for determining when services performed or earnings derived from services demonstrate an individual’s ability to engage in substantial gainful activity. In determining whether an individual is able to engage in substantial gainful activity by reason of his earnings, where his disability is sufficiently severe to result in a functional limitation requiring assistance in order for him to work, there shall be excluded from such earnings an amount equal to the cost (to such individual) of any attendant care services, medical devices, equipment, prostheses, and similar items and services (not including routine drugs or routine medical services unless such drugs or services are necessary for the control of the disabling condition) which are necessary (as determined by the Commissioner of Social Security in regulations) for that purpose, whether or not such assistance is also needed to enable him to carry out his normal daily functions; except that the amounts to be excluded shall be subject to such reasonable limits as the Commissioner of Social Security may prescribe. Notwithstanding the provisions of subparagraph (B), an individual whose services or earnings meet such criteria shall be found not to be disabled. The Commissioner of Social Security shall make determinations under this title with respect to substantial gainful activity, without regard to the legality of the activity.

(F) Notwithstanding the provisions of subparagraphs (A) through (D), an individual shall also be considered to be disabled for purposes of this title if he is permanently and totally disabled as defined under a State plan approved under title XIV or XVI as in effect for October 1972 and received aid under such plan (on the basis of disability) for December 1973 (and for at least one month prior to July 1973), so long as he is continuously disabled as so defined.

(G) In determining whether an individual’s physical or mental impairment or impairments are of a sufficient medical severity that such impairment or impairments could be the basis of eligibility under this section, the Commissioner of Social Security shall consider the combined effect of all of the individual’s impairments without regard to whether any such impairment, if considered separately, would be of such severity. If the Commissioner of Social Security does find a medically severe combination of impairments, the combined impact of the impairments shall be considered throughout the disability determination process.

TITLE 89: SOCIAL SERVICES
CHAPTER I: DEPARTMENT OF HEALTHCARE AND FAMILY SERVICES
SUBCHAPTER b: ASSISTANCE PROGRAMS
PART 120 MEDICAL ASSISTANCE PROGRAMS
SECTION 120.347 TREATMENT OF TRUSTS AND ANNUITIES

Section 120.347 Treatment of Trusts and Annuities

a) This Section applies to trusts established on or after August 11, 1993.

b) A trust is any arrangement in which a grantor transfers property to a trustee or trustees with the intention that it be held, managed or administered by the trustee or trustees for the benefit of the grantor or designated beneficiaries. A trust also includes any legal instrument or device that is similar to a trust, including an annuity.

c) A person shall be considered to have established a trust if resources of the person were used to form all or part of the principal of the trust and the trust is established (other than by will) by any of the following:

1) the person;

2) the person's spouse; or

3) any other person, including a court or administrative body, with legal authority to act on behalf of or at the direction of the person or the person's spouse.

d) This Section does not apply to the following trusts:

1) an irrevocable trust containing the resources of a person who is determined disabled (as provided in Section 120.314) and under age 65 that is established by a parent, grandparent, legal guardian or court for the sole benefit (as defined in Section 120.388(m)(2)) of the person, if language contained in the trust stipulates that any amount remaining in the

trust (up to the amount expended by the Department on medical assistance) shall be paid to the Department upon the death of the person. This exclusion continues after the person reaches age 65 as long as the person continues to be disabled but any additions made by the person to the trust after age 65 will be treated as a transfer of assets under Sections 120.387 and 120.388. If the trust contains proceeds from a personal injury settlement, any Department charge (as described at 89 Ill. Adm. Code 102.260) must be satisfied in order for the trust to be excluded under this subsection; or

2) Effective July 1, 2012, an irrevocable trust containing the resources of a person who is determined disabled (as provided in Section 120.314) that is established and managed by a non-profit association that pools funds but maintains a separate account for each beneficiary that is established by the disabled person, a parent, grandparent, legal guardian or court for the sole benefit of the disabled person, if language contained in the trust stipulates that any amount remaining in the trust (up to the amount expended by the Department on medical assistance) that is not retained by the trust for reasonable administrative costs related to wrapping up the affairs of the subaccount shall be paid to the Department upon the death of the person. After a person reaches age 65, any funding by or on behalf of the person to the trust shall be treated as a transfer of assets for less than fair market value unless the person is a ward of a county public guardian or the State guardian pursuant to Section 13-5 of the Probate Act of 1975 [755 ILCS 5] or Section 30 of the Guardianship and Advocacy Act [20 ILCS 3955] and lives in the community or the person is a ward of a county public guardian or the State guardian pursuant to Section 13-5 of the Probate Act of 1975 or Section 30 of the Guardianship and Advocacy Act and a court has found that any expenditures from the trust will maintain or enhance the person's quality of life. If the trust contains proceeds from a personal injury settlement, any Department charge (as described at 89 Ill. Adm. Code 102.260) must be satisfied in order for the trust to be excluded under this subsection (d).

The Save Medicaid Resources Together (SMART) Act of 2012 Addendum C

On June 14, 2012, Illinois Governor Pat Quinn signed the Smart Act into law. The Smart Act (Public Act 097-0689) became effective on July 1, 2012. This law affects how the Medicaid program is administered in Illinois by the Illinois Department of Healthcare & Family Services. The law was brought about Deficit Reduction Act of 2005 that required changes to the management of Medicare and Medicaid funded services for cost savings.

As important in 2012, Illinois was projected to have a shortfall of about $2.7 billion for its Medicaid program. Thus the State felt it necessary to change the Medicaid program, including making cuts to what nursing homes are paid to care for their residents. The news media reported that changes were coming. A headline on the first page of The Chicago Tribune on April 17, 2012, read, *"Big cuts loom for Medicaid in Illinois.*"

Here are some of the changes brought on by the SMART Act

1. Nursing homes and institutions for the mentally ill will receive less money for taking care of their residents.
2. The community spouse resource allowance was reduced to **$109,560**. (It had been $113,640 from January 1, 2012 until the changes under the Smart Act.)
3. The community spouse maintenance needs allowance (the monthly amount of income that a community spouse may have) was reduced to **$2,739**. (It had been $2,849 from January 1, 2012 until the changes under the Smart Act.)
4. A prepaid irrevocable funeral/burial contract may be up to **$5,874** (not counting what part is for the "burial space", as the burial space is not limited to any specific amount).
5. Prescriptions for long-term care residents have been reduced to a 14-day supply for each drug.
6. Other changes affect what services a person might receive. For example, a person on Medicaid can only get a new pair of glasses every two years. Adult dental care is only available for emergency extraction of teeth. Adult podiatric care is only available for diabetics.

The following pages provide parts of the Smart Act that are applicable to persons in long-term care facilities (nursing homes or assisted living facilities).

The Smart Act states the following with regard to Pooled Trusts:

"Notwithstanding any other provision of this Code to the contrary, an irrevocable trust containing the resources of a person who is determined to have a disability shall be considered exempt from consideration. Such trust must be established and managed by a non-profit association that pools funds but maintains a separate account for each beneficiary. The trust may be established by the person, a parent, grandparent, legal guardian, or court. It must be established for the sole benefit of the person and language contained in the trust shall stipulate that any amount remaining in the trust (up to the amount expended by the Department on medical assistance) that is not retained by the trust for reasonable administrative costs related to wrapping up the affairs of the subaccount shall be paid to the Department upon the death of the person. After a person reaches age 65, any funding by or on behalf of the person to the trust shall be treated as a transfer of assets for less than fair market value unless the person is a ward of a county public guardian or the State guardian pursuant to Section 13-5 of the Probate Act of 1975 or Section 30 of the Guardianship and Advocacy Act and lives in the community, or the person is a ward of a county public guardian of the State guardian pursuant to Section 13-5 of the Probate Act of 1975 or Section 30 of the Guardianship and Advocacy Act and a court has found that any expenditures from the trust will maintain or enhance the person's qualify of life. If the trust contains proceeds from a personal injury settlement, any Department charge must be satisfied in order for the transfer to the trust to be treated as a transfer for fair market value."

Supplemental Needs Distribution Guide   Addendum D

The following are examples of allowable distributions under Life's Plan Incorporated Trusts

Community Supports:

- Advocacy, oversight, monitoring or private case management, legal services
- Respite, day care
- Some crisis intervention, guardianship
- Vocational rehabilitation or habilitation not covered by Medicaid or Medicare
- Room and board incidental to long term care or medical care (i.e., a portion of charges for nursing home, CBRF, residential care, etc.), not covered by Medicaid.
- Personal care attendant
- Support and service coordination
- Social services, including supervision and reporting if not covered by Medicaid

Recreation & Leisure:

- Participation in sports, hobbies, recreational events, cultural events
- Vacations and travel
- Club memberships
- Movies (No refreshments, including sodas allowed)
- Television and cable, computer, Internet services, telephone, tablets
- Costs to visiting friends, companions, Guardian
- Musical instruments
- Life coach
- Special occasions

Maintenance:

- Clothing
- Home improvements and repairs
- Furniture and appliances
- Housekeeping services
- Lawn care, snow removal
- Storage
- Income taxes
- Grooming (e.g. manicure; haircut)

Transportation:

- Purchase of a car
- Car repair, maintenance and insurance
- Accessibility-related equipment and modifications
- Bus, rail and cab fare/Uber/Lyft services

Medical Care (not covered by Medicaid:

- Therapies
- Prescription drugs and medications (not covered by Medicaid)
- Medical supplies and equipment
- Assistive technology/devices
- Dental treatment, preventive health and devices
- Eyeglasses, contacts and optometry services
- Medical treatments not medically necessary
- Co-pays, deductibles, etc.
- Housing modifications for accessibility
- Ambulance or other medical transportation

Insurance:

- Life Insurance (MUST be for the benefit of beneficiary, others cannot be designated beneficiary of policy)
- Supplemental health insurance

Education & Training:

- Conferences and seminars
- Publication subscriptions
- Class tuition, books and supplies
- Software
- Music class

And other expenses to provide dignity, purpose and enjoyment for the beneficiary

THE FOLLOWING EXPENSES CANNOT BE PAID FOR SSI REPIENTS

Supplementary Food and Shelter:

- Rent
- Groceries
- Cost difference between shared and private room
- Property taxes
- Basic utilities (e.g. heat, gas, electric, water, sewer and garbage removal)

Note: Any recurring payments or big ticket purchases (e.g. car, TV, furniture) should be reviewed by your Trust administrator before purchasing. Certain distribution requests may require a "denial" by Medicaid or insurance providers to be considered a supplemental need. This is a partial, not exhaustive, list of possible uses of your trust fund assets.

Summary: H.R.647 — 113th Congress (2013-2014) Addendum E

Passed House amended (12/03/2014)

Achieving a Better Life Experience Act of 2014 or the ABLE Act of 2014 - **Title I: Qualified ABLE Programs** - (Sec. 101) States as the purposes of this title to: (1) encourage and assist individuals and families in saving private funds for the purpose of supporting individuals with disabilities to maintain health, independence, and quality of life; and (2) provide secure funding for disability-related expenses of beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, title XVI (Supplemental Security Income) and title XIX (Medicaid) of the Social Security Act, the beneficiary's employment, and other sources.

(Sec. 102) Amends the Internal Revenue Code to exempt from taxation a qualified ABLE program established and maintained by a state, or by an agency or instrumentality of the state, to pay the qualified disability expenses related to the blindness or disability of a program beneficiary, including expenses 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, and expenses for oversight and monitoring, funeral and burial expenses.

Requires officers and employees who have control of the qualified ABLE program to make reports as required by the Secretary of the Treasury. Imposes an additional 10% tax on individuals who do not use distributions from an ABLE account for disability expenses. Subjects ABLE accounts to the penalty tax for excess contributions and for failure to file required reports.

(Sec. 103) Requires amounts in ABLE accounts to be disregarded in determining eligibility for means-tested federal programs, except distributions for housing expenses under the supplemental security income program and for amounts in an ABLE account exceeding $100,000. Suspends the payment of supplemental security income benefits to an individual during any period in which such individual has excess resources in an ABLE account, but does not suspend or affect the Medicaid eligibility of such individual.

(Sec. 104) Amends the bankruptcy code to exclude funds placed in an account of a qualified ABLE program from a bankruptcy estate, but only if: (1) the designated beneficiary of such account was a child, stepchild, grandchild, or step grandchild of the debtor; (2) such funds are not pledged or promised to any entity in connection with any extension of credit and are not excess contributions to an ABLE account; and (3) such funds do not exceed $6,225 during a specified time period.

(Sec. 105) Amends the Internal Revenue Code to permit contributors to or beneficiaries of a qualified tuition program (529 program) to direct the investment of contributions to a 529 program (or any earnings thereon) up to two times in any calendar year (currently, no investment direction is allowed).

T**itle II: Offsets**- (Sec. 201) Amends title II (Old Age, Survivors, and Disability Insurance Benefits) of the Social Security Act to change the age at which disability benefits are no longer subject to reductions from 65 to the normal retirement age range as set forth in such Act.

(Sec. 202) Amends title XVIII (Medicare) of the Social Security Act to: (1) accelerate the beginning date for adjustments of relative value targets for misvalued services in Medicare physician fee schedules from 2017 to 2016; and (2) treat items and services for vacuum erection systems furnished on and after July 1, 2015, in the same manner as erectile dysfunction drugs for purposes of defining covered drugs under Medicare part D.

(Sec. 204) Amends the American Taxpayer Relief Act of 2012 to delay to January 1, 2025, the implementation of oral-only end stage renal disease (ESRD)-related drugs in the ESRD prospective payment system.

(Sec. 205) Amends the Internal Revenue Code to increase the Inland Waterways Trust Fund financing rate to 29 cents per gallon for fuel used after March 31, 2015.

(Sec. 206) Amends the Internal Revenue Code to treat Internal Revenue Service (IRS)-certified professional employer organizations (PEOs) as employers for employment tax purposes (thus allowing such PEOs to pay wages and collect and remit payroll taxes on behalf of an employer).

Sets forth IRS certification requirements for PEOs, including independent financial review and reporting requirements. Requires a PEO, each year, to post a bond equal to the greater of 5% of the PEO's liability during the preceding calendar year (not exceeding $1 million) or $50,000.

(Sec. 207) Amends the Internal Revenue Code to exclude dividends received by a U.S. shareholder from a controlled foreign corporation from the definition of "personal holding company income" for purposes of personal holding company taxation.

(Sec. 208) Amends the Internal Revenue Code to require an annual inflation adjustment to tax penalty amounts for: (1) failure to file a tax return or pay tax, (2) failure to file certain information returns or registration statements, (3) noncompliance of tax return preparers, (4) failure to file partnership or S corporation returns, and (5) failure to file correct information returns or correct payee statements.
(Sec. 209) Amends the Internal Revenue Code to increase from 15 to 30% the rate of the continuous levy on payments due to a Medicare provider or supplier for overdue taxes.

Resources

Nadworny, John Haddad, Cynthia	The Special Needs Planning Guide, 2007 p. 202-209
Lovelace, Renee	Pooled Trust Options, A Guidebook produced by the National Plan Alliance, p. 21-27, p. 32-39 & p. 54-55
The ARC	POOLED TRUST PROGRAMS FOR PEOPLE WITH DISABILITIES, A GUIIDE FOR FAMILIES, 2002
Chamberlin, Darcy	"Special Needs Trusts and Alternatives" IICLE Special Needs Planning Basic and Advanced
Jackins, Barbara, Blank, Richard Shulman, Ken Macy, Peter Onello, Harriet	SPECIAL NEEDS TRUST, A Guide for Trustees Administration Manual, 2005 Edition

Stetson University, ed., Special Needs Trust conference materials 2014, Stetson University College of Law, October 2013-14.

Stetson University, ed., Special Needs Trust pre-conference materials Pooled Trust intensive Stetson University College of Law, October 2015.

Websites

SSA Procedure Operations Manual System (POMS) –
SI 01120.203 Exceptions to Counting Trusts Established on or after 1/1/00
https://secure.ssa.gov/apps10/poms.nsf/lnx/0501120203!opendocument#b

89 IL Admin Code Treatment of Trusts
http://www.ilga.gov/commission/jcar/admincode/089/089001200H03470R.html

The Academy of Special Needs Planners consists of Special Needs Planners is to provide a general overview of strategies for parents and others to plan for their own futures and for those of family members with special needs. The Academy has have one of the few national listing sites on pooled trusts: *http://specialneedsanswers.com/pooled-trust*

The Special Needs Alliance (SNA) is a national, not for profit organization of attorneys dedicated to the practice of disability and public benefits law. Individuals with disabilities, their families and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena. http://specialneedsalliance.com/home

Illinois ABLE program

The Illinois ABLE program is a tax-advantaged investment program that provides persons with blindness or disabilities the option to save for disability-related expenses without putting their federal means tested benefits at risk. Illinois ABLE is a member of the National ABLE Alliance, a partnership of 14 states representing over one quarter of the population of the United States. The goal of the National ABLE Alliance is to provide the most robust ABLE services possible at the lowest cost to account owners. http://illinoistreasurer.gov/Individuals/ABLE

ABLE National Resource Center

The ABLE National Resource Center (ANRC) is a collaborative whose supporters share the goal of accelerating the design and availability of ABLE accounts for the benefit of individuals with disabilities and their families. We bring together the investment, support and resources of the country's largest and most influential national disability programs. http://www.ablenrc.org/

Special Needs Alliance Trustee Handbook

The Special Needs Alliance offers a free booklet on administering special needs trusts. In plain English and Spanish, it can help a trustee understand the choices and obligations in managing a Special Needs Trust. http://specialneedsalliance.com/free-trustee-handbook