Administering a Special Needs Trust

A Handbook For Trustees (2024 Edition)

SPECIAL NEEDS ALLIANCE

Attorneys for special needs planning.

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Administering a Special Needs Trust: A Handbook for Trustees

Introduction and Definition of Terms

"Special Needs" trusts are complicated and can be hard to understand and administer. They are like other trusts in many respects—the general rules of trust accounting, law and taxation apply—but unlike more familiar trusts in other respects. The very notion of "more familiar" types of trusts will, for many, be amusing—most people have no particular experience dealing with formal trust arrangements, and special needs trusts are often established for the benefit of individuals who would not otherwise expect to have experience with trust concepts.

The essential purpose of a special needs trust is usually to improve the quality of an individual's life without disqualifying him or her from eligibility for public benefits. Therefore, one of the central duties of the trustee of a special needs trust is to understand what public benefits programs might be available to the beneficiary and how receipt of income, or provision of food or shelter, might affect eligibility. Because there are numerous programs, competing (and sometimes even conflicting) eligibility rules, and at least two different types of special needs trusts to contend with, the entire area is fraught with opportunities to make mistakes. Because the stakes are often so high—the public benefits programs may well be providing all the necessities of life to the beneficiary—a good understanding of the rules and programs is critically important.

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Before delving into a detailed discussion of special needs trust principles, it might be useful to define a few terms:

GRANTOR (sometimes "Settlor" or "Trustor")—the person who establishes the trust and generally the person whose assets fund the trust. There might be more than one grantor for a given trust. The tax agency may define the term differently than the public benefits agency. Special needs trusts can make this term more confusing than other types of trusts, since the true grantor for some purposes may not be the same as the person signing the trust instrument. If, for example, a parent creates a trust for the benefit of a child with a disability, and the parent's own money funds the trust, the parent is the grantor. In another case, where a parent has established a special needs trust to handle settlement proceeds from a personal injury lawsuit or improperly directed inheritance, the minor child (through a guardian) or an adult child will be the grantor, even though he or she did not decide to establish the trust or sign any trust documents.

TRUSTEE—the person who manages trust assets and administers the trust provisions. Once again, there may be two (or more) trustees acting at the same time. The grantor(s) may also be the trustee(s) in some cases. The trustee may be a professional trustee (such as a bank trust department or a lawyer), or may be a family member or trusted adviser—though it may be difficult to qualify a non-professional to serve as trustee.

BENEFICIARY—the person for whose benefit the trust is established. The beneficiary of a special needs trust will usually (but not always) be disabled. While a beneficiary may also act as trustee in some types of trusts, a special needs trust beneficiary will almost never be able to act as trustee.

DISABILITY—for most purposes involving special needs trusts, "disability" refers to the standard used to determine eligibility for Social Security Disability Insurance or Supplemental Security Income benefits: the inability to perform any substantial gainful employment.

INCAPACITY (sometimes Incompetence)—although "incapacity" and "incompetence" are not interchangeable, for our purposes they may both refer to the inability of a trustee to manage the trust, usually because of mental limitations. Incapacity is usually important when applied to the trustee (rather than the beneficiary), since the trust will ordinarily provide a mechanism for transition of power to a successor trustee if the original trustee becomes unable to manage the trust. Incapacity of a beneficiary may sometimes be important as well. Not every disability will result in a finding of incapacity; it is possible for a special needs trust beneficiary to be disabled, but not mentally incapacitated. Minors are considered to be incapacitated as a matter of law. The age of majority differs slightly from state to state, though it is 18 in all but a handful of states.

REVOCABLE TRUST—refers to any trust which is, by its own terms, revocable and/or amendable, meaning able to be undone, or changed. Many trusts in common use today are revocable, but special needs trusts are usually irrevocable, meaning permanent or irreversible.

IRREVOCABLE TRUST—means any trust which was established as irrevocable (that is, no one reserved the power to revoke the trust) or which has become irrevocable (for example, because of the death of the original grantor).

SOCIAL SECURITY DISABILITY INSURANCE—sometimes referred to as SSDI or SSD, this benefit program is available to individuals with a disability who either have sufficient work history prior to becoming disabled or are entitled to receive benefits by virtue of being a dependent or survivor of a disabled, retired, or deceased insured worker. There is no "means" test for SSDI eligibility, and so special needs trusts may not be necessary for some beneficiaries—they can qualify for entitlements like SSD and Medicare even though they receive income or have available resources. SSDI beneficiaries may also, however, qualify for SSI (see below) and/or Medicaid benefits, requiring protection of their assets and income to maintain eligibility. Of course, just because a beneficiary's benefits are not means-tested, it does not follow that the beneficiary will not benefit from the protection of a trust for other reasons.

SUPPLEMENTAL SECURITY INCOME—better known by the initials "SSI," this benefit program is available to low-income individuals who are disabled, blind or elderly and have limited income and few assets. SSI eligibility rules form the basis for most other government program rules, and so they become the central focus for much special needs trust planning and administration.

MEDICARE—one of the two principal health care programs operated and funded by government—in this case, the federal government. Medicare benefits are available to all those age 65 and over (provided only that they would be entitled to receive Social Security benefits if they chose to retire, whether or not they actually are retired) and those under 65 who have been receiving SSDI for at least two years. Medicare eligibility may forestall the need for or usefulness of a special needs trust. Medicare recipients without substantial assets or income may find that they have a difficult time paying for medications (which historically have not been covered by Medicare but began to be partially covered in 2004) or long-term care (which remains largely outside Medicare's list of benefits).

MEDICAID—the second major government-run health care program. Medicaid differs from Medicare in three important ways: it is run by state governments (though partially funded by federal payments), it is available to those who meet financial eligibility requirements rather than being based on the age of the recipient, and it covers all necessary medical care (though it is easy to argue that Medicaid's definition of "necessary" care is too narrow). Because it is a "means-tested" health care program, its continued availability is often the central focus of special needs trust administration. Because Medicare covers such a small portion of long-term care costs, Medicaid eligibility becomes centrally important for many persons with disabilities.

The Most Important Distinction

Two entirely different types of trusts are usually lumped together as "special needs" trusts. The two trust types will be treated differently for tax purposes, for benefit determinations, and for court involvement. For most of the discussion that follows, it will be necessary to first distinguish between the two types of trusts. The distinction is further complicated by the fact that the grantor (the person establishing the trust, and the easiest way to distinguish between the two trust types) is not always the person who actually signs the trust document.

"Self-Settled" Special Needs Trusts

Some trusts are established by the beneficiary (or by someone acting on his or her behalf) with the beneficiary's funds for the purpose of retaining or obtaining eligibility for public benefits—such a trust is usually referred to as a "self-settled" special needs trust. The beneficiary might, for example, have received an outright inheritance, or won a lottery. By far the most common source of funds for "self-settled" special needs trusts, however, is proceeds from a lawsuit—often (but not always) a lawsuit over the injury that resulted in the disability. Another common scenario requiring a person with a disability to establish a self-settled trust is when they receive a direct inheritance from a well-intentioned, but ill-advised relative.

A given trust may be treated as having been "established" by the beneficiary even if the beneficiary is completely unable to execute documents, and even if a court, family member, or lawyer representing the beneficiary actually signed the trust documents. The key test in determining whether a trust is self-settled is to determine whether the beneficiary had the right to outright possession of the proceeds prior to the act establishing the trust. If so, public benefits eligibility rules will treat the beneficiary as having set up the trust even though the actual implementation may have been undertaken by someone else acting on their behalf. Virtually all special needs trusts established with funds recovered in litigation or through a direct inheritance will be "self-settled" trusts.

Self-settled special needs trusts are different from third-party trusts in two important ways. First, self-settled trusts must include a provision directing the trustee, if the trust contains any funds upon the death of the beneficiary, to pay back anything the state Medicaid program has paid for the beneficiary. Second, in many states, the rules governing permissible distributions for self-settled special needs trusts

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are significantly more restrictive than those controlling third-party special needs trusts.

Because Social Security law specifically describes self-settled special needs trusts, these instruments are sometimes referred to by the statutory section authorizing transfers to such trusts and directing that trust assets will not be treated as available and countable for SSI purposes. That statutory section is 42 U.S.C. §1396p(d)(4)(A), and so self-settled special needs trusts are sometimes called, simply, "d4A" trusts.

"Third-party" Special Needs Trusts

The second type of special needs trust is one established by someone other than the person with disabilities (usually, but not always, a parent) with assets that never belonged to the beneficiary. It is often used, when proper planning is done for a disabled person's family, to hold an inheritance or gift. Without planning, a well-meaning family member might simply leave an inheritance to an individual with a disability. Even though it may be possible to set up a trust after the fact, the funds will have been legally available to the beneficiary. That means that any trust will probably be a "self-settled" special needs trust, even though the funds came from a third party.

Parents, grandparents and others with the foresight to leave funds in a third party special needs trust will provide significantly better benefits to the beneficiary who has a disability. This type of trust will not need to include a "payback" provision for Medicaid benefits upon the beneficiary's death. During the beneficiary's life, the kinds of payments the trust can make will usually be more generous and flexible.

> Some trusts are established by the beneficiary for the purpose of retaining or obtaining eligibility for public benefits with the beneficiary's funds. By far the most common source of funds for "self-settled" special needs trusts is proceeds from a lawsuit—often (but not always) a lawsuit over the injury that resulted in the disability.

The "Sole Benefit" Trust

Although there are two primary types of special needs trusts, there is actually a third type that might be appropriate under certain unusual circumstances. Because Medicaid rules permit applicants to make unlimited gifts to or "for the sole benefit of" disabled children or spouses, some individuals with assets may choose to establish a special needs trust for a child or grandchild with disabilities in hopes of securing eligibility for Medicaid for both themselves as grantor and for the disabled beneficiary. A number of states are very restrictive in their interpretation of the "sole benefit" requirement, so that such trusts are rarely seen. In many ways they look like a hybrid of the two other trust types; they may be taxed and treated as third-party trusts, but require a payback provision like a self-settled trust (at least in some states).

The Second Most Important Distinction

Once the type of trust is determined, the next important issue is discerning the type of government program providing benefits. Some programs (like SSDI and Medicare) do not impose financial eligibility requirements; a beneficiary receiving income and all his or her medical care from those two programs might not need a special needs trust at all, or might benefit from more flexibility given to the trustee. A recipient of SSI and/or Medicaid, however, may need more restrictive language in the trust document and closer attention on the part of the trustee.

SSDI/Medicare Recipients

Neither Social Security Disability Insurance benefits nor Medicare are "means–tested." Consequently, it may be unnecessary to create a special needs trust for someone who receives benefits only from those two programs. After 24 months of SSDI eligibility, the beneficiary will qualify for Medicare benefits as well, so it may be appropriate to provide special needs provisions to get the SSDI recipient through that two-year period, during which he or she may rely on Medicaid for medical care. Restrictive special needs trust language may actually work against an SSDI beneficiary if it prevents distribution of cash to the beneficiary in all circumstances; an SSDI recipient will almost always benefit from broad language giving more discretion to the trustee.

Some SSDI/Medicare recipients may also receive SSI and/or Medicaid benefits. It may be critically important for those individuals to have strict special needs language controlling use of any assets or income that would otherwise be available. As the Medicare prescription drug benefit evolves over the next few years, this concern may be somewhat lessened—but for the moment, it remains true that availability of the drug coverage provided by Medicaid is critically important to many Medicare recipients.

Even an SSDI/Medicare beneficiary who does not receive any SSI or Medicaid benefits may be a good candidate for special needs trust planning. Future developments in public benefits programs, including housing, are uncertain, but constant budget pressure may well make benefits now taken for granted completely or partially indexed to income and/or assets in the future. Medical conditions also change, of course, and some persons with disabilities living in the community who presently receive adequate support from

Medicare may one day become dependent on Medicaid for services not available under Medicare–like long term care.

SSI/Medicaid Recipients

Most special needs trust beneficiaries are eligible for (or seeking eligibility for) Supplemental Security Income payments. In many states, receipt of SSI payments automatically qualifies one for Medicaid eligibility. Many other government programs explicitly rely on SSI eligibility rules as well, so that SSI eligibility rules become the central concern for those charged with administering special needs trusts.

Veterans' Benefits

"Veterans' benefits" is the term used to describe the benefits available to veterans, the surviving spouses, children or parents of a deceased veteran, dependents of disabled veterans, active duty military service members, and members of the Reserves or National Guard. These benefits are administered by the U.S. Department of Veterans Affairs ("VA").

The benefits available to veterans include monetary compensation (based on individual unemployability or at least ten-percent disability from a service-connected condition), pension (if permanently and totally disabled or over the age of 65 and have limited income and net worth), health care, vocational rehabilitation and employment, education and training, home loans and life insurance. Although the pension is available to low-income veterans, it is important to note that some income, such as child's SSI or wages earned by dependent children, is excluded when determining the veteran's annual income. Also keep in mind that a service-connected disability payment will not offset SSDI, but any VA disability payment will offset SSI.

The benefits available to dependents and survivors of the veteran include Dependency and Indemnity Compensation ("DIC") and, in certain circumstances, home loans.

Transferring a VA recipient's assets into a special needs trust may not be fully effective. According to VA interpretation, the assets of such a trust will be counted as part of the claimant's net worth when calculating an improved pension. It is important to remember that the VA may place a "freeze" on new enrollees in order to manage the rapid influx of new veterans or older veterans who did not previously enroll for services. Therefore, it is important to evaluate current and future need for VA services in order to anticipate and plan for a situation where a person is otherwise eligible for VA benefits but, due to a freeze, cannot receive services. Under a new law, attorneys must become accredited with the VA to advise clients in this area.

> Parents, grandparents and others with the foresight to leave funds in a third-party special needs trust will provide significantly better benefits to a beneficiary with disabilities.

Subsidized Housing

FEDERAL SUBSIDIZED HOUSING

The U.S. Department of Housing and Urban Development ("HUD") provides opportunities to low-income individuals and families to rent property at a cost that is lower than the open market. This is especially important to those people who are expected to pay for their shelter costs (rent or mortgage, plus utilities) with their insufficient SSI income. There are two issues to consider when evaluating the role of special needs trusts and subsidized housing: the initial eligibility for subsidized housing and the rent determination.

Eligibility for subsidized housing depends on the family's annual income. Annual income includes earned income, SSI, SSDI, pension, unemployment compensation, alimony, and child support, among other items. Annual income also includes unearned income, which is comprised, in part, of interest generated by assets. If the family has net family assets in excess of $5,000, the annual income includes the greater of the actual income derived from all net family assets or a percentage of the value of such assets based on the current passbook savings rate, as determined by HUD.

Assets that are not included as income upon receipt are lump sums, such as inheritances and insurance settlements for losses (although the income they generate will be countable), reimbursement for medical expenses, PASS set-asides, work training programs funded by HUD and the income of a live-in aide.

In general, to qualify for federal subsidized housing, an individual's countable income may not exceed eighty percent of the median income in the area to be considered "low income", and the individual's income may not exceed fifty percent of the median income to be considered "very low income". The result is a disparity in eligibility depending on where the person resides within the county, state, and region of the country.

There is no asset limit to be eligible for federal subsidized housing, although as described above, if countable assets are greater than $5,000, the interest income generated will be counted towards eligibility. If a person transfers an asset for less than its fair market value, then HUD will treat the asset as if it were still owned by the individual for two years after the transfer. HUD will assume that the asset generates income at the passbook rate and will include that income in calculating the individual's rent. Therefore, it is very likely that HUD will treat transfers to a special needs trust as a transfer for less than fair market value and, for the next two years, will include

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the interest generated by the special needs trust as income to the individual, either at the passbook rate or the actual earnings, whichever is greater.

Special Needs Trusts are excluded from family assets and the income generated by the trust assets is not included once the two-year penalty period has expired. It is important to note that, similar to other programs such as Medicaid and SSI, "regular" distributions from a special needs trust, even if made to a third-party provider, will be treated as countable income, even if used for non-food and shelter items.

In many states, receipt of SSI payments automatically qualifies one for Medicaid eligibility. Many other government programs explicitly rely on SSI eligibility rules as well, so that SSI eligibility rules become the central concern for those charged with administering special needs trusts.

The second issue relating to subsidized housing and a special needs trust is determining the monthly rent. Generally, an individual/family's rent will be thirty percent of their adjusted gross income. Similar to treatment under the threshold eligibility rules, the special needs trust and the income generated by trust assets are excluded, but "regular" distributions made directly to the beneficiary (as opposed to a third-party provider of goods or services) will be considered as income.

SECTION 8

Section 8 is a voucher program that is administered by HUD but managed by local public housing authorities ("PHA") or metropolitan housing authorities ("MHA"). The tenant pays their rent, typically thirty percent of their net adjusted income, to the landlord. The PHA pays the remaining balance due, which is called the voucher, to the landlord. The rent is based on the market value for the area and established by the PHA according to payment standards issued by HUD.

While a family member generally cannot serve as a Section 8 landlord, it is possible for a special needs trust to do so, even if the trustee is a family member. Although there are special rules applicable to a Section 8 landlord, it can be a beneficial relationship. The trust beneficiary would pay rent to the trustee (using the thirty percent of income rule) and the PHA would pay the remainder to the trustee.

It is important to investigate how your local housing authority's rules differ from the general rules listed above.

Temporary Assistance for Needy Families ("TANF")

TANF provides assistance and work opportunities to needy families. TANF is administered locally by the states, but is overseen by The Office of Family Assistance ("OFA"), which is located in the United States Department of Health and Human Services, Administration for Children and Families. TANF is a result of combining two other programs: Aid to Families with Dependent Children ("AFDC") and Job Opportunities and Basic Skills Training ("JOBS"). Because TANF is administered on a local level, the program and eligibility rules vary greatly from state to state. However, it is safe to assume that distributions directly made to the beneficiary of a special needs trust, or to the beneficiary's family if a minor, may be considered income and will impact eligibility for TANF.

Other Means-Tested Benefits Programs

State supplements to SSI and other government benefit programs, like vocational rehabilitation services, also play important roles in the lives of many individuals with disabilities. Because the welter of eligibility programs is confusing and the reach of most other programs is not as broad as those described in detail here, those other programs are not described in any depth. In analyzing the proper approach to establishment or administration of a special needs trust, however, care should be taken to consider all the available program resources and restrictions on use of trust funds mandated by those programs.

Eligibility Rules for Means- Tested Programs

As previously noted, the primary program with financial eligibility restrictions is SSI, the Supplemental Security Income program. Because the concepts are central to an understanding of other eligibility rules, and because many other programs explicitly utilize SSI standards, the SSI rules become the most important ones to grasp. They are described here in a general way, with a few notations where other programs (particularly long-term care Medicaid) differ from the SSI rules.

Income

SSI eligibility requires limited income and assets. SSI rules have a simple way of distinguishing between income and assets: Money received in a given month is income in that month, and any portion of that income remaining on the first day of the next month becomes an asset. SSI rules also distinguish between what is "countable" or "excluded," "regular" or "irregular," and "unearned" or "earned" income. "Countable" income means that it is used to compute eligibility and benefit amount. "Excluded" means that it is not counted. "Regular" means that it is received on a periodic basis, at least two or more times per quarter or in consecutive months, and "irregular" or "infrequent" means that it is not periodic or predictable. "Unearned" means that it is passively received, such as SSDI benefits or bank account interest. "Earned" means that work is performed in exchange for the income. An SSI recipient is permitted to receive a small amount of any kind of income ($20 per month) without reducing benefits. That amount is sometimes referred to as the SSI "disregard" amount.

Each classification or grouping has a somewhat different rule, and it is an understatement to call these income rules "confusing." Any unearned income reduces the SSI benefit by the amount of the income, so investment income or gifted money simply reduces the benefit dollar for dollar, less the disregard. Earned income is treated more favorably, only reducing benefits by about half of the earnings. This is designed to encourage SSI recipients to return to the workforce. Keeping in mind that disability is defined as "unable to perform any substantial gainful activity," it is easy to see that any significant amount of earned income will eventually imperil SSI eligibility and, since trust administration does not usually involve earned income in any event, we will not attempt to deal with those issues here.

SSI also has a concept of "in-kind support and maintenance" (ISM) that is central to much understanding of special needs trust administration. Any payment from a third party (including a trust) for necessities of life—food or shelter (note that the federal government deleted "clothing" from the list of necessities in March 2005) to a third party provider of goods or services—will be treated as countable income, albeit subject to special rules for calculating its effect.

The effect of receiving ISM on SSI benefits is different from the receipt of cash distributions. Where as cash payments reduce the SSI payment dollar for dollar, ISM reduces the benefit by the lesser of the presumed maximum value of the items provided or an amount calculated by dividing the maximum SSI benefit by three and adding the $20 disregard amount.

For 2024, the maximum federal SSI benefit for a single person is $943. One third of that amount is $314.33, and so the maximum reduction in benefits caused by ISM (no matter how high the value) is $334.33 per month. The meaning of that confusing collection of information is best illustrated using an example (CAUTION: some states provide SSI supplemental payments that affect this calculation).

Consider John, who is disabled as a result of his serious mental illness. He has no work history, and he does not qualify for SSDI. He is an adult, living on his own. He qualifies for the maximum federal SSI benefit of $943; he lives in a state which does not provide an SSI supplement.

If John's mother gives him $100 cash per month (for food and cigarettes), he is required to report that as countable unearned income each month. Although SSI may take two or three months to accomplish the adjustment, the program will eventually withhold $80 ($100 minus the $20 disregard) from his benefit for each month in which his mother makes a cash gift to him. The same result will obtain if John's mother is trustee of a special needs trust for John and the cash comes from that trust.

If, however, John's mother does not give him the $100 directly, but instead purchases $70 worth of food and $30 worth of video games each month, only the food will affect his SSI payment—reducing it by $50 ($70 minus the $20 disregard). If she purchases $20 worth of food and $80 worth of video games, there will be no effect at all—the food purchase is within the $20 monthly disregard amount. Similarly, if she purchases $20 worth of video games and $30 worth of movie tickets, there will be no effect—provided that the movie tickets cannot be turned in for cash (because if the movie tickets can be converted to cash, John could—even if he does not—convert the movie tickets into payment for food or shelter).

In other words, the effect of John's mother's payments to him or for his benefit changes with the nature of her payments. Any cash she provides to him (over the $20 monthly amount ignored by SSI) reduces his SSI payment directly. Direct purchase of items other than food or shelter does not affect his SSI, so long as the purchased items cannot be converted to food or shelter. Finally, any payment she makes for food or shelter reduces his SSI check as well, but not as harshly as cash payments directly to John.

Now suppose that John's mother decides to give up on trying to work around the strictures of SSI rules, and she simply pays his rent at an adult care facility that provides his meals. Assume that the facility costs her $1500 per month, which she pays from her own pocket. Because of the ISM rules, John's SSI benefit will be reduced by only $334.33 per month, and so his SSI check will be reduced to $608.67. Critically important, however, John will still qualify for Medicaid benefits in most states because he receives some amount of SSI. If the adult care home payment comes from a special needs trust for John's benefit, the same result will occur, assuming that the room and board portion of the payment exceeds $334.33. Incidentally, the same result will also obtain if John's mother simply takes him in and allows him to live and eat with her without charging him rent.

Now assume that John does have a work history before becoming disabled, and that he qualifies to receive $700 per month from SSDI. Because he has been receiving SSDI for more than two years, he also qualifies for Medicare. Because his countable income is less than $943, he continues to receive $263 in SSI benefits ($20 of the SSD is disregarded), and qualifies for Medicaid as well (we will ignore the effect

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of the QMB and SLMB programs for qualified, special low-income Medicare beneficiaries, and the Medicare Part B premium which would ordinarily be withheld from his SSDI check). Now if John's mother pays his rent at the adult care home, or takes him into her own home, he will lose his SSI altogether—since he is receiving less than $334.33 per month from SSI, the effect of the ISM rules will be to knock him off the program. Unless he separately qualifies for Medicaid, he will also lose his coverage under that program. The income strictures are the same or similar for other programs, with one important exception. In some states, but not all, eligibility for community or long-term care Medicaid is also dependent on countable income. The income tests vary. In some, you can "spend down" excess income over the limit to become eligible. In others, if countable income exceeds the benefit "cap" (like SSI), you cannot become eligible at all.

Some states also attempt to limit expenditures from self-settled (and even third-party) special needs trusts, and can require amendments to the language of those trusts in order to allow eligibility. While a good argument can be made that the Medicaid program does not have that ability, as a practical matter, the trustee of the special needs trust will have to either litigate that issue or acquiesce in the Medicaid agency's demands.

Assets

The limitation on assets for SSI eligibility may be somewhat easier to master, or at least to describe. A single person must have no more than $2,000 in available resources in order to qualify for SSI. Some types of assets are not counted as available (called "non-countable"), including the beneficiary's home, one automobile, household furnishings, prepaid burial amounts plus up to $1500 set aside for funeral expenses (or life insurance in that amount), tools of the beneficiary's trade, and a handful of other, less important items. Each of these categories of assets is subject to special rules and exceptions, so it is easy to become tangled in the asset eligibility structure.

Deeming

The SSI program considers portions of the income and assets of non-disabled, ineligible parents of minor disabled children and of an ineligible spouse living with the SSI recipient as available, and countable for eligibility purposes. This is called "deeming". A certain portion of the ineligible person's income and assets is considered as necessary for his or her own living expenses, and therefore is excluded.

As soon as a child reaches age 18, parental deeming no longer occurs, even if the child continues to live in the household. If spouses voluntarily separate and live in different households, then deeming from the separate spouse or parent also ends. However, in both instances, if the separate person continues to provide support or maintenance to the SSI eligible individual, it will still count as income as described above unless a Court orders it to be deposited directly into the trust. There is also a limited exception to all parental deeming for a severely disabled minor child returning home from an institution or whose condition would otherwise qualify them for institutionalization, which is called a waiver.

"I Want to Buy a…" or "I Want to Pay for…"

What do these complicated rules mean for expenditures from a special needs trust? In-kind purchases, meaning purchase of goods or services for the benefit of the beneficiary, only potentially affect the SSI benefit amount, and not Medicaid benefits, although the Medicaid agency may restrict expenditures for approved things. There are a number of specific purchases that frequently recur:

Home, Upkeep and Utilities

Keep in mind that SSI's in-kind support and maintenance (ISM) rules deal specifically with payments for "food and shelter." The Social Security Administration includes only these items as food and shelter:

1. Food
2. Mortgage (including property insurance required by the mortgage holder)
3. Real property taxes (less any tax rebate/credit)
4. Rent
5. Heating fuel
6. Gas
7. Electricity
8. Water
9. Sewer
10. Garbage removal

The rules make special note of the fact that condominium assessments may in some cases be at least partial payments for water, sewer, garbage removal and the like.

In other words, a payment for rent will implicate the ISM rules, as will monthly mortgage payments. The outright purchase of a home, whether in the name of the beneficiary or the trust, will not cause loss of SSI (although it may reduce the beneficiary's SSI benefit for the single month in which the home is purchased). This brings up another consideration. Purchase of a home in the trust's name will subject it to a Medicaid "payback" requirement on the death of the beneficiary, whereas purchase in the name of the beneficiary may allow other planning that will avoid the home becoming part of the payback. This complicated interplay of trust rules, ISM definition, estate-recovery rules, and home ownership makes this area of special needs trust administration particularly fraught with difficulty.

However, the Medicaid state agency's treatment of distributions from special needs trusts may differ from the Social Security interpretation—especially when the beneficiary of a self-settled trust is eligible for Medicaid benefits. For example, contrary to putting the house in the individual's name, a state may require that any purchase of a home by such a trust would result in title being held in the trust's name, thereby ensuring that the state will at least receive the proceeds from the sale of the residence upon the death of the beneficiary.

Clothing

Until March 7, 2005, purchase of clothing by a trust was considered as ISM for SSI, similar to shelter and food. Since then, a clothing purchase for the beneficiary will not affect the benefit amount or eligibility, whether the clothing in question is special garments related to the disability or just ordinary street clothes and shoes. Not all state Medicaid regulations reflect this change.

> As soon as a child reaches age 18, parental deeming no longer occurs even if the child continues to live in the household.

Phone, Cable, and Internet Services

Other than those utilities listed above, there is no federal limitation on utility payments. In other words, the trust can pay for cable, telephone, high-speed internet connection, newspaper, and other "utilities" not on the list.

Vehicle, Insurance, Maintenance, Gas

Purchase of a vehicle and maintenance (including gas and insurance) is permitted under federal law. Note that there is a mechanical difficulty in providing gasoline without providing cash that could be converted to food or shelter. One technique which has worked well has been to arrange for the beneficiary to have a gas-company credit card. Because eligibility for such cards is easier to meet, and because the cards cannot be used to purchase groceries, administration of the credit account is easier to set up and monitor, and the card can then be billed directly to the trust.

Some state Medicaid agencies put limitations on the value, type, and title ownership of vehicles, such as only allowing a vehicle valued at up to $5,000, handicapped-equipped, or requiring a lien in favor of the payback trust on the title. The SSI program does not specifically require or monitor such limitations.

Pre-paid Burial/Funeral Arrangements

Nothing in federal law prohibits or restricts use of special needs trust funds for purchase of burial and funeral arrangements during the beneficiary's lifetime— except to the extent that the beneficiary has access to the funds used to pay for the arrangements, and thereby subject to the asset limitations affecting SSI recipients. State Medicaid agencies may limit the value of the burial contract. It is important to ask for an "irrevocable, pre-paid" funeral plan.

Tuition, Books, Tutoring

No limit under either federal or state law. This is an excellent use of special needs trust funds.

Travel and Entertainment

Once again, no limit except that there may be some concern about payment for hotels. When the beneficiary still maintains a residence at home, the hotel stay and restaurant may be considered "shelter" and "food" expenses. Some states may impose limitations on companion travel not found in federal law. These might include not allowing recipients to have the special needs trust pay for more than one traveling companion, the companion must be necessary to provide care, and the companion may not be a person obligated to support the beneficiary such as a minor beneficiary's parent. Note that foreign travel can have two other adverse effects: (1) airline tickets to foreign destinations, if refundable, will be treated as being convertible into food and shelter, and (2) if an SSI recipient is out of the country for more than a month, he or she may lose eligibility until return. For those reasons, foreign travel, unlike domestic travel, usually must be limited in time.

Household Furnishings and Furniture

The trust can be used to purchase appliances, furniture, fixtures and the like. Before March 2005, there was a theoretical concern in the SSI program that the value of household furnishings might exceed an arbitrary limit and affect the beneficiary's eligibility; that value limit has now been removed.

Television, Computers and Electronics

There is no specific limitation on purchase of household televisions or other electronic devices, although under SSI rules the individual is only allowed to own "ordinary household goods" that are not kept for collectible value and are used on a regular basis. The trust can also provide a computer for the beneficiary, plus software and upgrades.

Durable Medical Equipment

There is no federal limitation on any medical related equipment, but individual states may limit purchase of some equipment as not being "necessary." Problem areas could be if the equipment could also be considered as recreational, such as a heated swimming pool needed for arthritic or other joint conditions.

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Care Management

No federal limitation, but many states attempt to limit payments for care or management if made to a family member or other relative, especially if there is an obligation of support (e.g., parents of minor children).

Therapy, Medications, Alternative Treatments

Same principle as durable medical equipment, above, so long as the state does not regulate the treatment, there is no federal limitation.

Taxes

No federal limitation, but states may attempt to direct trust language on what taxes can be paid for, such as taxes incurred as a result of trust assets or at the death of the beneficiary. Since it is difficult to imagine an SSI or Medicaid beneficiary having significant non-trust income, it is hard to see how this limitation is so much troublesome as it is quarrelsome.

Legal, Guardianship and Trustee Fees

At least some states allow legal, guardianship, and trustee fees to be paid from the trust, although some federal law indicates that payment of guardian's fees or guardian's attorney fees may really benefit the guardian and not the beneficiary. Payments for trust administration expenses, including the trust's attorney's fees, are clearly permissible under both federal and state law, and are rarely limited beyond reasonableness standards.

> It is generally beneficial for a self-settled special needs trust to be a grantor trust. This is true because the tax rates for non-grantor trusts are tightly compressed, and the highest marginal tax rate on income is reached very quickly for trusts.

Loans, Credit, Debit and Gift Cards

Receipt of a "loan" will not count as income for the SSI or Medicaid programs, which means that a trust can make a loan of cash directly to a beneficiary. There are rules that must be followed for loans to be valid and non-countable. There must be an enforceable agreement at the time that the loan is made that the loan will be paid back at some point, which usually means that it should be in writing. The agreement to pay back cannot be based on a future contingency such as, "I only have to pay it back if I win the lottery..." Finally, the loan must be considered as "feasible," meaning that there is a reasonable expectation that the beneficiary will have the means at some point to pay back the loan.

If a loan is forgiven, then it would count as income at that time. Also, if the beneficiary still has the loaned amount in the following month, it will then count as a resource. However, school loans are not countable as income or as a resource so long as the funds are spent for tuition, room and board, and other education-related expenses within nine months of receipt.

Since goods or services purchased with a credit card are actually a "loan" that must be paid back to the credit card company, they are also not considered as income to the beneficiary at time of purchase. As long as the beneficiary doesn't sell the goods for cash, there is also the added advantage that the trust can pay back the credit card company without the payment counting as income, except for purchases that are considered as food or shelter. Food and shelter related purchases use the same ISM countable income rules (and particularly the countable income limits) described above.

Use of a debit card by a beneficiary when purchases are made for payment through a trust-funded bank account is income to the beneficiary for the amount accessed. The total amount in the account available to be accessed could possibly be a countable resource. Is a gift card purchased by a trust and provided to a beneficiary considered to be a distribution of income, a line of credit to a vendor (similar to a credit card), or just access for in-kind purchase of goods or services on behalf of a beneficiary by the trust? SSI rules are not yet clear on this point, and it is probable that different Social Security and Medicaid offices will treat the use of debit and gift cards differently until precise guidelines are provided by the agencies. The safe approach is to use them in a very limited way; if they are to be used at all, keep receipts for all special needs items, and be prepared for adverse treatment.

Trust Administration and Accounting

Actual administration of a special needs trust is in most respects similar to administration of any other trust. A trustee has a general obligation to account to beneficiaries and other interested parties. Tax returns may need to be filed (though not always), and tax filing requirements will be based on the tax rules, not special needs trust rules. Some special needs trusts, but by no means all, will be subject to court supervision and control.

Trustee's Duties

As with general trust law requirements, the trustee of a special needs trust has an obligation not to self-deal, not to delegate the trustee's duties impermissibly, not to favor either income or remainder beneficiaries over one another, and to invest trust assets prudently. The obligations of a trustee are well-discussed in several centuries of legal precedent, and cannot be taken lightly. Legal counsel (and professional investment, tax and accounting assistance) will be required in administration of almost every special needs trust.

A few cardinal trust rules bear special mention:

NO SELF-DEALING

As with other trusts, the trustee of a special needs trust is prohibited from self-dealing. That means no investment of trust assets in the trustee's business or assets, no mingling of trust and personal assets, no borrowing from the trust, no purchase of goods or services (by the trust) from the trustee (other than, of course, trust administration services), and no sale of trust assets to the trustee. The same strictures also apply to the trustee's immediate family members, and the existence of an appraisal, or the favorable terms of a transaction, do not change these rules.

IMPARTIALITY

Because the trust has both an "income" beneficiary (the person with disabilities) and a "remainder" beneficiary (the state, in the case of a Medicaid payback trust, or the individuals who will receive assets when the income beneficiary dies), the trustee has a necessarily divided loyalty. It is important to remain impartial as between the trust's beneficiaries. Thus, investment in assets exclusively designed to maximize income at the expense of growth, or vice versa, may violate the trustee's duty to the negatively affected class of beneficiaries. Note that a trust may, by its terms, make clear that the interests of one or the other class of beneficiaries should be paramount—though such language will probably earn the disapproval of the Medicaid agency in any self-settled trust which must be submitted to Medicaid for approval.

DELEGATION

Generally speaking, a trustee may delegate functions but may not avoid liability by doing so. In other words, while the trustee may hire investment advisers, tax preparers and the like, he or she will remain liable for any failures by such professionals.

Some states do limit the trustee's liability. For example, in states which have adopted the Uniform Prudent Investor Act, delegating investment authority pursuant to the Act will limit the trustee's liability so that he or she will only be required to carefully select and monitor the investment adviser.

INVESTMENT

Any trustee should be familiar with the principles of Modern Portfolio Theory, with its emphasis on risk tolerance and asset diversification. A trustee who holds himself, herself, or itself out as having special expertise in investments or asset management will be held to a higher standard, but any trustee will be required to understand and implement prudent investment practices. Some courts will institute an investment policy that requires a percentage of assets to be held in fixed income investments and the remainder in securities (e.g., a 60/40 split is common).

> A trustee has a general obligation to account to beneficiaries and other interested parties. Tax returns may need to be filed (though not always), and tax filing requirements will be based on the tax rules, not special needs trust rules.

Bond

A trustee, especially one who administers a special needs trust supervised by a probate court, may need to be bonded. Bond is a type of insurance arrangement whereby the trustee pays a premium in order to guarantee that the trustee manages the trust and carries out his or her fiduciary duties correctly. The bond premium is an acceptable expense of the trust, and need not come out of the trustee's own pocket. If the trustee fails to exercise his or her fiduciary duty and the trust loses money as a result, the insurance company that issued the bond will compensate the trust and take action to collect from the trustee.

The bond premium depends on multiple factors, including the credit history of the trustee and the value of the trust. Most corporate trustees are exempt from posting bond. Individual trustees must "post bond"; that is, provide written documentation to the probate court that the individual is bonded. The bond is typically issued for a set period of time, for example one year, and at the expiration of the time period, the trustee must pay an additional premium or show the bond issuer that bond is no longer required by the probate court.

It is possible in most states, at least when the trust is supervised by a court, to ask the court for permission to deposit the assets in a restricted or "blocked" account with a financial institution rather than posting bond. While this circumvents the issue of being bonded, the financial institution should require a certified copy of the court's order authorizing the expenditure of funds prior to making a distribution from the special needs trust. This can result in frequent in-person trips to the bank by the trustee, although it avoids the sometimes costly bond premium.

Titling Assets

The trust assets should not be titled in the beneficiary's name except in limited circumstances, such as when it is advantageous to title the home in the individual's name. Typically, the trust assets should be titled in the name of the

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trustee. For example, if James Jones is the trustee of the Lisa Martin Special Needs Trust, and that trust was signed on March 15, 2007, then the trust assets should be titled as follows: "James Jones, Trustee of the Lisa Martin Special Needs Trust u/a/d March 15, 2007" ("u/a/d" means "under agreement dated").

It is important that most assets not be held in James Jones's or Lisa Martin's name individually. If the assets are not titled properly, then the assets may be counted as a resource, or the interest earned counted as income, by the agencies that administer means-tested government benefits, which will frustrate the purpose of the special needs trust, as well as contribute to confusion during tax preparation. Additionally, as discussed in further detail below, it may also be important to request a separate Tax ID number for the trust as well as properly title the assets.

Accounting Requirements

A trustee is required to provide adequate accounting information to beneficiaries of the trust. That requirement generally means annual accountings. While there is no specific form required for accountings if the trust is not under court supervision, it is important to provide enough information that a reader could determine the nature and amount of any payment or investment. For some trusts, a simple "check register" accounting may be sufficient, showing interest income and the names of payees, with dates and amounts. Any trust with significant assets or diverse investments, however, should provide a thorough accounting.

> The trustee of a special needs trust is prohibited from self-dealing. That means no investment of trust assets in the trustee's business or assets, no mingling of trust and personal assets, no borrowing from the trust, no purchase of goods or services (by the trust) from the trustee (other than, of course, trust administration services), and no sale of trust assets to the trustee.

Regular, complete accountings are critical. A beneficiary is generally foreclosed from later raising objections to investments or expenditures if he or she received adequate disclosure in the annual accounting at the time. In other words, thorough accounting can limit the trustee's later exposure to claims by beneficiaries, and therefore benefits the trustee.

In addition to the accounting requirements to the beneficiary, the trustee may be required to provide an annual or biennial accounting to the probate court. The trustee should use the county-specific forms available upon request from the court, and may also be required to provide the court with copies of bank statements and cancelled checks or receipts as evidence of trust distributions and deposits. This requires the trustee to be organized or be prepared to pay potentially substantial bank fees for duplicate account statements or cancelled checks.

Reporting to Social Security

The simple term "income" has different meanings in trust accounting, tax preparation, and public benefits eligibility determinations. Trustees sometimes raise concerns that thorough trust accountings (to SSI, especially) may result in suspension of benefits, or that tax return information may be used to terminate SSI or other benefits. While such things undoubtedly do occur, Social Security workers are increasingly likely to be relatively sophisticated about such distinctions, and willing to work through any problems. In a general way, then, it is better to disclose more fully to Social Security rather than withhold any information. Annual accountings of any self-settled trust naming an SSI recipient as beneficiary should be provided to Social Security. Any third-party trust which makes significant distributions for the benefit of an SSI recipient should probably be provided to Social Security, just to prevent later problems that could have been headed off. If distributions disrupt eligibility, the problem is with the distribution, not with the accounting.

If the beneficiary receives only SSDI and not any concurrent SSI, there is no point in providing accounting information to Social Security, because SSDI benefits are not means-tested. If the trust is a third-party trust, the trustee may not have any obligation to provide accounting information, though the beneficiary may (if the beneficiary receives SSI and trust distributions invoke the ISM rules) be required to do so.

Although it no longer occurs as regularly, some Social Security eligibility workers may misunderstand the effect of special needs trust expenditures or terms and reduce or eliminate benefits improperly. When this does occur, it should be possible to remedy the error, but the beneficiary may suffer for months (or years) while the system works out the problem. Far better to head off problems in advance, rather than have to spend substantial resources and time resolving them after the fact. Be aware that fees for a trustee's time spent directly dealing with Social Security on the beneficiary's behalf may be subject to approval by SSA.

Reporting to Medicaid

If the beneficiary resides in a state where the receipt of SSI results in the beneficiary also being automatically enrolled in Medicaid, then no separate accounting requirement need be made to the Medicaid agency. However, if the individual is in a state where SSI and Medicaid are not interrelated, then it may be necessary to account to both agencies. The Medicaid consumer (or their guardian) is required to notify Medicaid of a change in resources or income within a set period of time, usually as short as ten days. This includes situations where the Medicaid consumer receives an inheritance or settlement and immediately transfers the funds to a special needs trust.

The trustee of a third-party special needs trust may not have the same duty to account, but may choose to provide accounting information to Medicaid rather than risk later disqualification of the beneficiary, even though Medicaid's power to consider trust expenditures may be subject to challenge.

Reporting to the Court

Many self-settled special needs trusts will be treated in essentially the same fashion as a conservatorship or guardianship of the estate. This is so because, typically, the court was initially asked to authorize establishment of the trust. Most courts expect any trust established by the court to remain under court supervision, including bonding, seeking authority to expend funds, and filing periodic accountings.

Even if the trust does not require court accounting, some consideration should be given to seeking court involvement. One great advantage of court supervision of the trust is that each year's accounting is then final as to all items described in that accounting (provided, of course, that the appropriate notice has been given to beneficiaries who might otherwise complain about the trust's administration and other court procedural requirements are followed).

The Court may also have a set fee schedule that governs the amount the trustee can be compensated for providing trust administration services.

Modification of Trust

As explained above, a special needs trust must be irrevocable in order for the trust to be considered an exempt resource. However, that does not preclude the trust itself from permitting the trustee to amend or modify the trust in limited ways, particularly as it relates to program eligibility for the beneficiary. This is particularly important since we cannot predict future changes to the laws governing means-tested benefits. The courts may also be willing to modify or terminate a trust whose purpose has been frustrated by law changes or other factors, such as the trust assets being valued at a nominal amount.

Wrapping up the Trust

If the special needs trust is a self-settled trust with a provision requiring repayment of Medicaid expenses, it will obviously be necessary to determine the "payback" amount upon the death of the beneficiary or termination of the trust. Because Medicaid's historical experience with these trusts is still slight, state agencies may have difficulty providing a reliable and final figure. The prudent trustee will request a written statement of the amount due, including evidence showing how it was calculated and a statement of authority to make the final determination. Once any payback issues have been addressed (and remember that most third-party special needs trusts will have no requirement of repayment to the state), then termination of the trust will follow the usual requirements of tax preparation and filing, final accounting and distribution according to the trust instrument. Remember, because Social Security requires that Medicaid reimbursement and certain tax liabilities must be squared away before the trustee may even pay for the beneficiary's funeral, purchase during the beneficiary's lifetime of an irrevocable pre-paid funeral is critical.

Income Taxation of Special Needs Trusts

Special needs trusts, like other types of trusts, can complicate income tax preparation. The first question to be addressed is whether—for income tax purposes–the trust is a "grantor" trust or not. Tax rules defining "grantor" trusts are neither simple nor intuitive, but fortunately there are some easy rules of thumb to apply, and they will work for most special needs trusts.

"Grantor" Trusts

A "grantor" trust is treated for tax purposes as a transparent entity. In other words, the grantor of a "grantor" trust is treated as having received the income directly, even though the accounts are titled to the trust and all income shows up in the name of the trust.

Generally speaking, a self-settled special needs trust will be a grantor trust if a family member is the trustee. If the trust names an independent trustee it may still be a grantor trust if one of several specific provisions exists in the trust. A qualified accountant or lawyer should be able to tell whether a given trust is a grantor trust at a glance. If it is, it remains a grantor trust for its entire life—or at least until the death of the grantor (when the trust may either terminate or convert into a non-grantor trust as to its new beneficiaries). Until the trust has been reviewed by an expert, assume that it is probably a grantor trust.

It is generally beneficial for a self-settled special needs trust to be a grantor trust. This is true because the tax rates for non-grantor trusts are tightly compressed, and the highest marginal tax rate on income is reached very quickly for trusts. The practical difference will be small if the trust actually makes distributions for the benefit of the beneficiary in excess of its annual taxable income, but the proper tax reporting approach should still be followed.

TAX ID NUMBERS

A grantor trust may, but need not, obtain an Employer Identification Number (an EIN). Some attorneys and accountants choose to secure an EIN in each case, while

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others resist doing so—either approach is defensible. Although banks, brokerage houses and other financial institutions may insist that the trust requires its own EIN, they are simply wrong. There is widespread confusion about the necessity for an EIN for irrevocable trusts, but a confident and well-informed trustee, attorney or accountant should be able to convince the financial institution that no separate EIN is required. Instead, the trustee can simply provide the financial institution with the grantor's Social Security number.

FILING TAX RETURNS

A grantor trust ordinarily will not file a separate tax return. If a grantor trust has been assigned an EIN, it may file an "informational" return. The return can include a paragraph indicating that the trust is a grantor trust, that all income is being reported on the beneficiary's individual return, and that no substantive information will be included in the fiduciary income tax return. Actually, completing the fiduciary income tax return is not an option for a grantor trust, although again there is much confusion on this point, even among some professionals.

Non-Grantor Trusts

Virtually all third-party, and some self-settled, special needs trusts will be non-grantor trusts. Because income will not be treated as having been earned by the beneficiary, a fiduciary income tax return (IRS form 1041) will be required.

TAX ID NUMBERS

A non-grantor trust will need to obtain its own EIN by filing a federal form SS-4. Nearly all third-party special needs trusts will be "complex" trusts—this designation simply means that the trust is not required to distribute all its income to the income beneficiary each year. Although the trust will be listed as "complex" on the SS-4, it may in fact alternate between "complex" and "simple" on each year's 1041.

FILING TAX RETURNS

The non-grantor trust must file a 1041 each year. All distributions for the benefit of the beneficiary are conclusively presumed to be of income first, so any trust expenditures in excess of deductions will result in a Form K-1 showing income imputed to the beneficiary. This should not cause particular concern, since Social Security (and even Medicaid) eligibility workers are increasingly likely to understand that "income" for tax purposes is different from "income" for public benefits eligibility purposes. Any tax liability incurred by the individual beneficiary as a result of this imputation can be paid by the trust, though the trustee may not have the authority to prepare and sign the individual's tax return.

Administrative and other deductible expenses on an individual tax return must reach 2% of the taxpayer's income before being deducted at all. The same is not true of a trust tax return, leading to a modest benefit to treatment as a non-grantor trust in some cases. This benefit may not offset the compressed income tax rates levied against non-grantor trusts, but each case will be different. The difficulty in determining the proper—and the best—income tax treatment is made worse when one adds the confusing option of treatment as a "Qualified Disability Trust."

Qualified Disability Trust

Beginning in 2002, Congress allowed some non-grantor special needs trusts to receive a modest income tax benefit. Trusts qualifying under Internal Revenue Code Section 642(b)(2)(C) receive a special benefit—they are granted a larger and special deduction on their federal income taxes. In tax year 2023 (that is, the taxes that will be paid in April, 2024) for example, a Qualified Disability Trust can deduct $4,700 before any tax payment is due. That figure is slated to increase each year. Once the trust deducts that amount from its income, any remaining income might then be passed through to the beneficiary's tax return; the beneficiary may well pay no tax, or a very low rate of tax.

Coupled with the greater flexibility available to non-grantor trusts in deducting administrative expenses, Qualified Disability Trust treatment may be advantageous in some cases. Typically, the Qualified Disability Trust election will be attractive when there is a fair amount of income on trust assets, and relatively few medical or other expenses incurred on behalf of the beneficiary. Careful review with a qualified income tax professional is usually necessary to determine whether to pursue Qualified Disability Trust treatment.

Seeking Professional Tax Advice

It should be apparent from this brief discussion of taxation of special needs trusts that professional tax preparation and advice are essential. Although most accountants are qualified to prepare fiduciary (trust) income tax returns, most do not have much experience in the field. A first question to ask a prospective accountant might be "How many 1041s do you typically prepare in a year?" Follow that with "Could you please explain the concept of Qualified Disability Trusts to me?" and you will quickly locate any truly proficient practitioner. You probably will not want to automatically reject an accountant who cannot tell you about Qualified Disability Trusts immediately, unless you are prepared to deal with an accountant in another city—there are simply not very many accountants or tax preparers who have ever had occasion to claim that status on any fiduciary income tax return.
As always, you can get some assistance in complicated special needs trust issues from the attorney who prepared the document, or the attorney who advises you as trustee. Members of the Special Needs Alliance® are usually among the very few who are familiar with these concepts, and your attorney may have worked with an accountant in your area who is familiar with the special tax treatment of these trusts.

For Further Reading

There are a handful of books and articles, and a growing number of websites, available to aid trustees of special needs trusts. Among our favorites:

Special Needs Trust Administration Manual: A Guide for Trustees, by Jackins, Blank, Macy and Shulman—this guide is among the best available. It was written by four Massachusetts lawyers, and is frankly focused on Massachusetts law and practice. Much of what the authors have to say, however, is applicable to special needs trusts in every state.

Special People, Special Planning: Creating a Safe Legal Haven for Families with Special Needs, by Hoyt and Pollock—provides some general advice and direction, but is more conversational than detailed. This volume also tends to focus on the "why" more than the "how", which is an important message but not as useful to someone who is already administering a special needs trust.

Special Needs Trusts: Protect Your Child's Financial Future, by Elias—this recent addition to the literature comes from Nolo Press, an organization that many lawyers find annoying at best. We disagree. This is a plain-language, straightforward explanation of special needs trusts from a lawyer who doesn't even practice in the area (his previous books for Nolo Press include explanations of bankruptcy, trademark and other areas of law).

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What You Need to Know About Being an Adult with Disabilities

A HANDBOOK FOR SELF-ADVOCATES, PARENTS, GUARDIANS, AND THEIR LOVED ONES

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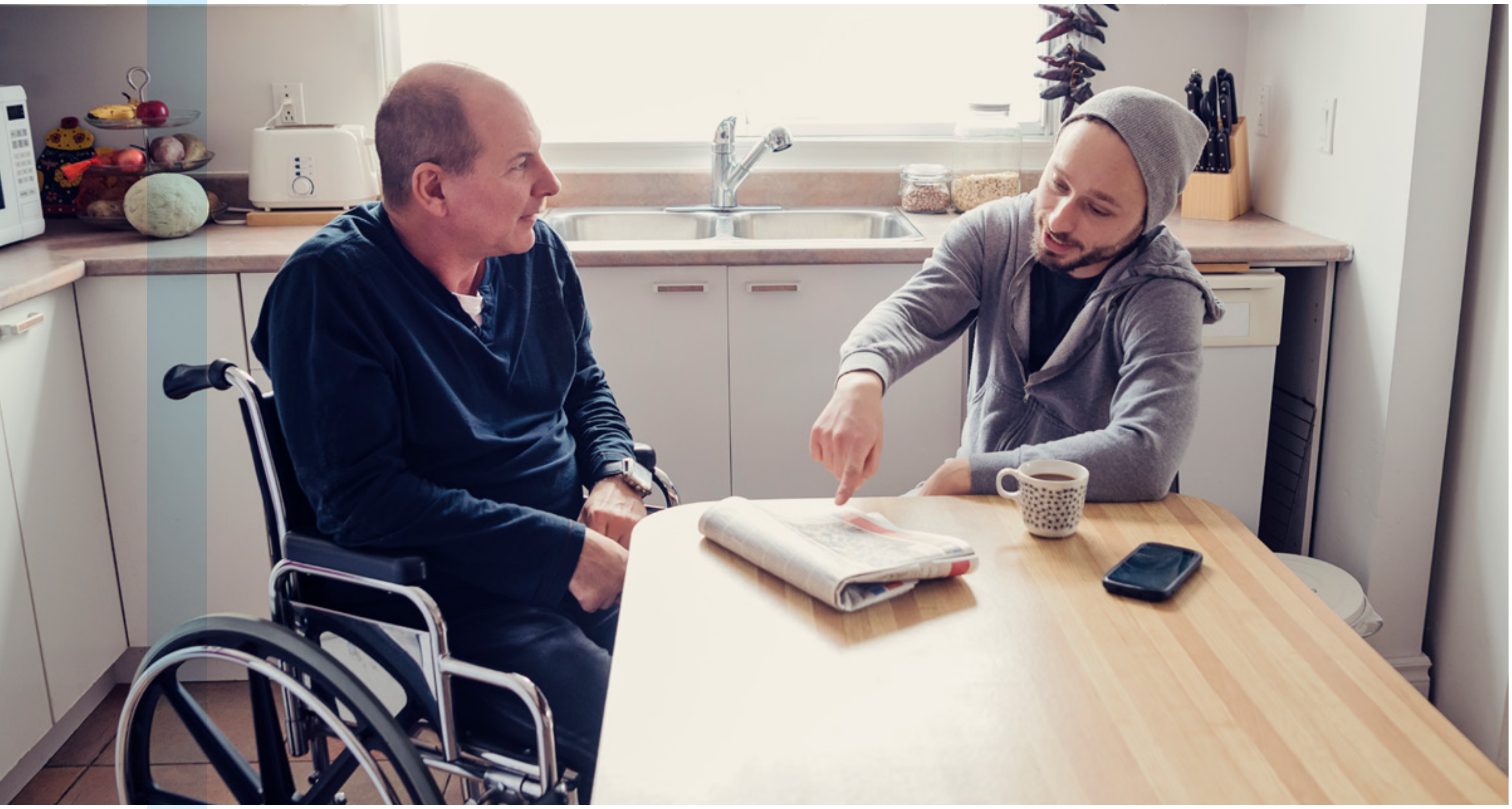
1 Introduction and Definition of Terms



INTRODUCTION

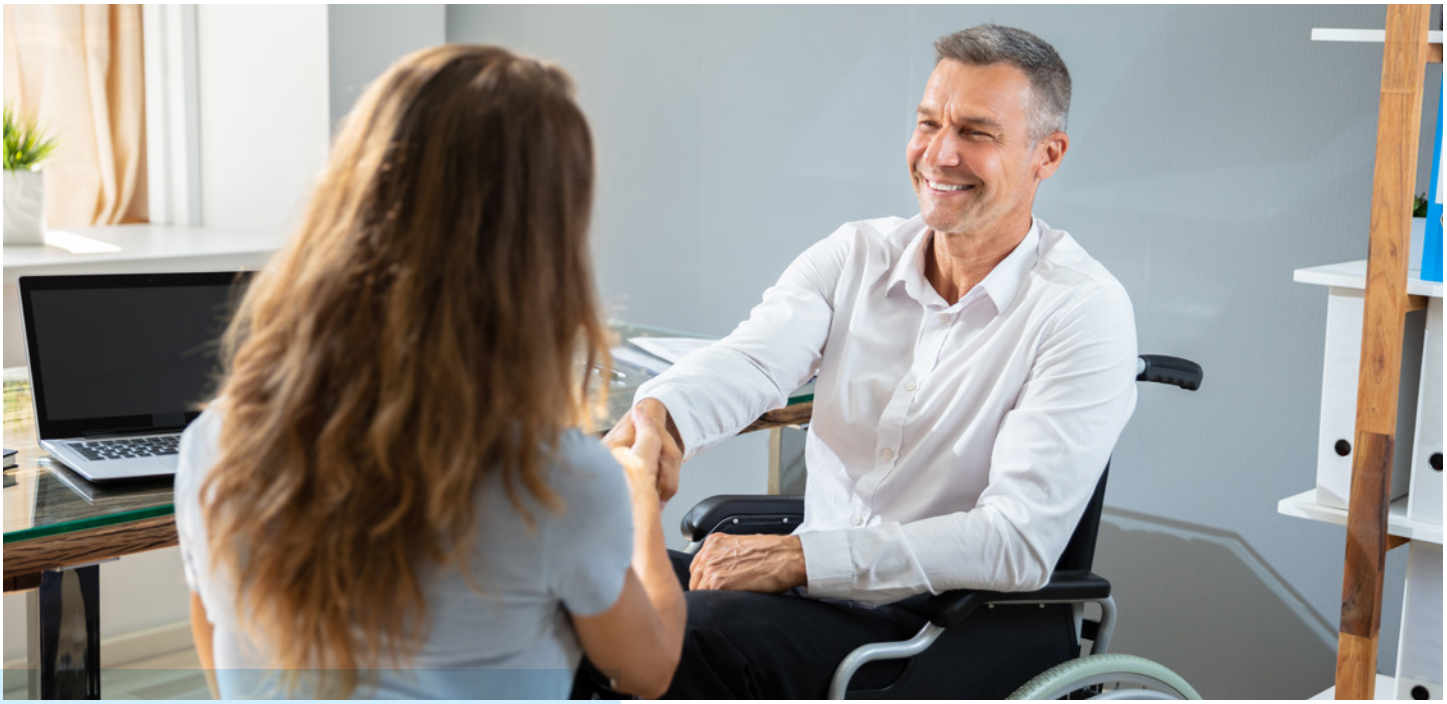
Supportive services and legal arrangements are only part of a person's transition to adulthood. Relationships, school, and housing involve additional perspectives that require coordination and understanding. Legal services should foster independence. Often, when the parents are the attorney's clients, it is easy to jump to the most protective arrangements that give the parents maximum control (e.g., guardianship, etc.). However, finding the best balance between autonomy and protection is important. For parents of children who are 16, 17, or 18 years old, legal and social services professionals can assist in achieving an appropriate balance between protection and independence.

The intent of this handbook is to explain some of the terms related to services and supports for people with disabilities, to introduce the process of transitioning from child services to adult services, and to provide guidance on options and resources that may be available to young adults with disabilities.

Because many laws are state specific, such as statutes regarding powers of attorney and guardianship, the reader is advised to seek legal counsel in their state. In some cases, this guide refers to uniform laws prepared by the Uniform Law Commission, and those uniform laws may be adopted by various states, often with additional state-specific amendments.

LEGAL DEFINITIONS

1. **Disability:** According to the federal Americans with Disabilities Act (ADA), a person with a disability is defined as “an individual having physical or mental impairment that substantially limits one or more major life activities.”
2. **Incapacity:** A lack of physical, mental, or cognitive ability that results in a person’s inability to manage their own personal care, property, or finances; a lack of ability to understand one’s actions when making a will or other legal document.
3. **Testamentary Capacity:** The mental or cognitive ability to understand and execute estate planning documents such as a will, trust, or power of attorney. In most states this is a low standard, and even a person who is subject to guardianship or conservatorship may have testamentary capacity. The requirements of testamentary capacity can vary from state to state, but generally testamentary capacity means the person must understand the following:
   - **a.** What they are doing (i.e., that a power of attorney allows someone else to make decisions for them, or that a will tells who the person would like to get their assets when they die);
   - **b.** Who they are appointing (i.e., be able to express why they want a certain person to be the decision maker);
   - **c.** What they are directing (that someone else gets to make decisions for them or that specific people will get their assets when they die); and,
   - **d.** What they are giving (the authority to make decisions or identify the assets they will be devising in their will).
4. **Agent:** The person who is authorized by another person (the principal) to deal with third parties and has the power to make decisions or take actions on behalf of the principal.
5. **Principal:** The main person who directs another person to act on their behalf or delegates their own decision-making to another person.
6. **Rights of Survivorship:** A feature of one type of joint ownership between two or more owners of an asset, such as a bank account or land. When the first owner dies, the remaining owner(s) own the decedent’s portion without taking any legal action.
   - For example, if John and Mary own a house as joint tenants with rights of survivorship and John dies, Mary becomes the sole owner. She doesn’t need a court ruling or a deed to establish her ownership.
7. **Public Benefits:** Public benefits are forms of assistance from the government, usually for individuals and families with limited resources and income.
8. **Medicaid:** A joint federal and state program that helps cover medical costs for some people with limited income and resources.
9. **Medicare:** The federal health insurance program for people who are 65 or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a transplant, sometimes called ESRD).
10. **Supplemental Security Income (SSI):** A federal program funded by U.S. Treasury general funds. The U.S. Social Security Administration (SSA) administers the program, but SSI is not paid for by Social Security taxes. SSI provides financial help to disabled adults and children who have limited income and resources.



11. **Social Security Disability Insurance (SSDI):** A federal government program that pays a cash benefit to individuals who have a sufficient work history prior to becoming disabled or are a dependent or survivor of a disabled, retired, or deceased insured worker. There is no resource limit for SSDI eligibility. Recipients of SSDI will also qualify for Medicare benefits after two years regardless of their age.

12. **Intellectual/Developmental Disability Waiver:** Often referred to as the "I/DD Waiver," this is a Medicaid program that provides services to individuals with a qualifying intellectual or developmental disability. These services can include housing, caregiving, day services, supported employment and therapies. Because it is a Medicaid program, the services provided to those receiving this benefit will differ from state to state.

13. **Guardian *ad Litem*:** Also referred to as a "GAL," an attorney appointed by the court to evaluate a case and report its findings and recommendations to the court. The evaluation, report, and recommendations are based upon the best interests of the protected person.

14. **Protective Arrangements:**

    - **Guardianship:** The legal role given to an individual to manage the personal decisions or resources of another person who cannot properly do so on their own. A child may need a legal guardian in situations where a parent is not available. An adult may need a guardian (also called a conservatorship in some states) when a court determines they have a disability that prevents them from exercising judgment or if the person becomes overly reckless or harmful to their welfare.

    - **Conservatorship:** The legal role given to an individual to manage the financial affairs of a person who is unable to handle them due to their incapacity. Some states use the term "guardian of the estate" for a court-appointed party to manage someone's financial matters.

    - **Power of Attorney:** A document that gives legal authorization for a designated person to make decisions about another person's property, finances, or medical care. The requirements for such will vary from state to state.

    - **Surrogate Decision Maker:** A decision maker for a patient who is unable to speak for themselves and has no legally authorized representative.

2 Decision-Making Options

There may be times when an individual with disabilities needs help making decisions about finances, healthcare, housing, and other life choices. Therefore, it is important to understand the various decision-making options that range from support from others to full guardianship.

Supported Decision-Making

Supported decision-making is a concept where an individual, who is presupposed to have capacity, maintains full decision-making authority and includes others to assist in gathering and evaluating information to make decisions about healthcare, living arrangements, and money matters. Supported decision-making arrangements can be informal, like when many of us seek advice from family and friends. In addition, a growing number of states have adopted statutes to formalize supported decision-making with written agreements.

In general, a written supported decision-making agreement includes the following:

- The individual's name and the name of the supporter;
- The duration of the agreement, which can be for a limited period or with no end date;
- The types of information the supporter can access, such as financial, educational, or medical; and,
- Any other documents to authorize the release of information, such as the Family Educational Rights and Privacy Act (FERPA) release for educational information or Health Insurance Portability and Accountability Act (HIPAA) release for medical information.

In addition to a supported decision-making agreement, it is a good idea for an individual to have power of attorney for healthcare and a financial power of attorney, in case the individual ever becomes incapacitated.

Powers of Attorney (Uniform Power of Attorney Act)

- Requirements for a Power of Attorney (POA) to be valid:
  - **i.** The principal must have capacity;
  - **ii.** It must be in writing;
  - **iii.** It must be signed by the principal; and,
  - **iv.** It must be notarized and may also need to be witnessed.
- Durable Power of Attorney
  - **i.** If a POA is "durable," it continues to be valid even if the principal becomes partially or fully incapacitated.

ii. If the POA is not durable, it only authorizes the agent to make decisions for the principal when the principal has the capacity to direct or authorize the agent's action. If the principal becomes incapacitated, the agent loses authority to make decisions for the principal.

iii. In many cases, a POA is effective immediately so that the agent may begin acting on behalf of the principal as soon as the POA is executed.

iv. Alternatively, a "springing" POA does not allow an agent to make decisions for the principal unless and until the principal is determined incapacitated. Usually this requires written documentation of incapacity by two healthcare providers, one of whom generally needs to be the principal's primary care provider.

- Duties, Responsibilities, and Limitations of a Financial POA

i. Typically, a financial POA describes the agent's authority to make decisions regarding the principal's assets. This can include accessing bank accounts, paying bills and taxes, selling or transferring real property, managing a business, and managing investment accounts.

ii. The POA must contain language specifically outlining the authority delegated to the agent. Without express language granting authority to do so, the agent CANNOT do any of the following:

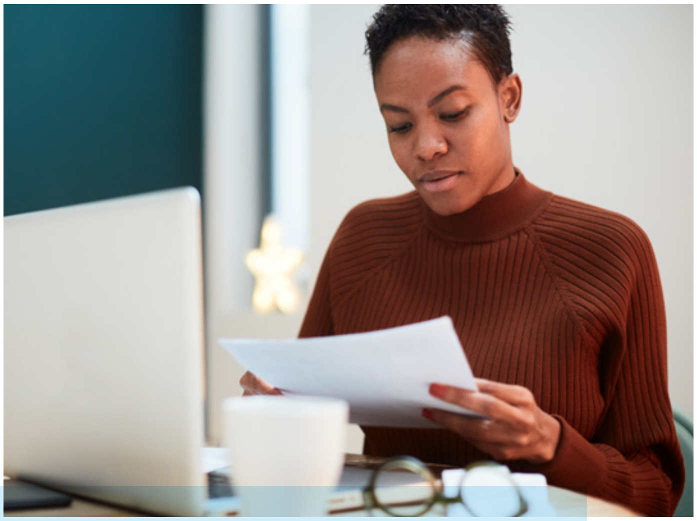
1. Create or change beneficiaries;
2. Alter rights of survivorship;
3. Give gifts;
4. Make changes to an inter vivos (living) trust;
5. Further delegate the authority created by the POA;
6. Control the principal's electronic communications; or
7. Waive certain entitlements for the principal.

iii. An agent owes the principal certain mandatory duties. These include:

1. Acting in accordance with the principal's reasonable expectations to the extent actually known by the agent and, otherwise, in the principal's best interest;
2. Acting in good faith; and
3. Acting only within the scope of authority granted in the POA.

iv. Except as otherwise provided in the POA, an agent that has accepted appointment shall:

1. Act loyally for the principal's benefit;
2. Act without creating a conflict of interest that impairs the agent's ability to act impartially in the principal's best interest;
3. Act with the care, competence, and diligence ordinarily exercised by agents in similar circumstances;
4. Keep a record of all receipts, disbursements, and transactions made on behalf of the principal;
5. Cooperate with a person that has authority to make healthcare decisions for the principal to carry out the principal's reasonable expectations to the extent actually known by the agent and otherwise act in the principal's best interest; and
6. Attempt to preserve the principal's estate plan, to the extent actually known by the agent, if preserving the plan is consistent with the principal's best interest based on all relevant factors, including:
    - The value and nature of the principal's property;
    - The principal's foreseeable obligations and need for maintenance;
    - Minimization of income, estate, inheritance, generation-skipping transfer and gift taxes; and,
    - Eligibility for a benefit, a program, or assistance under a statute or regulation.



- Duties, Responsibilities, and Limitations of a Healthcare POA:
  i. Typically, an agent under a healthcare POA is responsible for making decisions regarding the agent's care including consenting or to medical treatment, medical testing, medical procedures, and surgical procedures. The agent may be responsible for making decisions regarding medications, residential placement, social activities, and interactions with family and friends.

  ii. If the document includes an end-of-life directive, the agent may also have the responsibility to enact the principal's wishes.

  iii. Unless related to the principal by blood, marriage or adoption, an agent typically may not be an owner, operator, or employee of a healthcare institution at which the principal is receiving care.

  iv. An agent shall make healthcare decisions in accordance with the principal's individual instructions, if any, and other wishes to the extent known to the agent. Otherwise, the agent shall make the decision in accordance with the agent's determination of the principal's best interest. In determining the principal's best interest, the agent shall consider the principal's personal values to the extent known to the agent.

  v. A written advance healthcare directive may also include the principal's nomination of a guardian of the person.

Surrogate Healthcare Decision Makers

- Some states, with significant variation across the country, have laws that provide a process and priority for the designation of surrogate healthcare decision makers.
- In the absence of a designated healthcare agent for an incapacitated person, a surrogate healthcare decision maker may be appointed to look out for the best interest of the patient. For that surrogate to be designated, pursuant to the Uniform Healthcare Decisions Act, two qualified healthcare professionals must determine that the patient lacks capacity to make their own healthcare decisions. One of these professionals shall be the primary care physician.
- For individuals with developmental disabilities, the second professional shall be a person whose training and expertise aid in the assessment of functional impairment (physician, physician assistant, social worker, psychologist, nurse). In the event an individual is assessed to lack capacity to make healthcare decisions, a surrogate healthcare decision maker may be required if there is no agent (i.e., no POA) or court-appointed guardian in place, or if the agent or guardian is not reasonably available.
- The Uniform Health Care Decisions Act contains specific provisions identifying who may or may not serve as a surrogate. At any time, an individual for whom a surrogate is designated may challenge the determination of the need for a surrogate or the designation of a specific person to act as surrogate, by a signed writing or by telling their healthcare provider (i.e., their doctor) that they do not agree with the designation of a healthcare surrogate. A challenge regarding an individual's capacity will prevail unless otherwise ordered by court proceedings.

The role of a surrogate healthcare decision maker is generally intended:

- To be short term;
- To address a current medical issue; and,
- To be without any long-term oversight of such an arrangement.

Therefore, it is suggested that guardianship be sought for someone whose lack of capacity is clinically determined to be long-term.

Generally, surrogate decision-making laws authorize surrogates to make decisions regarding:

- The selection and discharge of healthcare providers and institutions;
- Approval or disapproval of diagnostic tests, surgical procedures, programs of medication, and orders not to resuscitate;
- Directions relating to life-sustaining treatment, including withholding or withdrawing life-sustaining treatment, and termination of life support; and,
- Directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of healthcare.

Guardianship (as it pertains to incapacitated adults, not minor children)

Typically, guardianship is a protective arrangement ordered by a court granting a third party the legal authority to make healthcare or person-centered decisions for an individual who has been determined to lack capacity to make healthcare decisions in their own best interests.

- Guardians often make decisions similar to those that a healthcare power of attorney would make such as consent to or refusal of medical treatment, medical testing, medical procedures, and surgical procedures. The guardian may be responsible for making decisions regarding medications, residential placement, social activities, and interactions with family and friends.
- Guardians are often monitored by the court through regular written reporting or hearings.
- A guardian can be a family member, friend, or an independent third-party.
- In many states, before a person can be found incapacitated by the court in a guardianship proceeding, there must be medical evidence to support the medical reason for the lack of capacity (i.e., dementia, traumatic brain injury, stroke, developmental disability, mental illness, or substance abuse).
- In many states, the alleged incapacitated person may also be represented in the guardianship proceeding by a Guardian *ad Litem* or by an attorney of their choosing or as appointed by the court.

Conservatorship/Guardian of the Estate

Typically, conservatorship is a protective arrangement ordered by a court granting a third party the legal authority to make financial decisions for an individual who has been determined to lack capacity to make financial decisions in their own best interests.

- Conservators often make decisions similar to those that a financial power of attorney would make, such as dealing with bank accounts, bill paying, real property, business decisions, investments, and taxes.
- Conservators are often monitored by the court through regular written reporting or hearings, and often are required to be bonded.
- A conservator can be a family member, friend, or an independent third-party.
- In many states before a person can be found incapacitated by the court in a conservatorship proceeding, there must be medical evidence to support the medical reason for the lack of capacity (i.e., dementia, traumatic brain injury, stroke, developmental disability, mental illness, or substance abuse).
- In many states, the alleged incapacitated person may also be represented in a conservatorship proceeding by a Guardian *ad Litem* or by an attorney of their choosing or as appointed by the court.
- Some states use the term "guardian of the estate" for a party appointed by the court to manage someone's financial matters.

3 Benefits and Services

Medicaid Waivers

Medicaid benefits are administered by each state, based on a combination of federal and state funding and federal and state laws for administering the programs. Some states request exceptions to federal rules (called "waivers") to allow flexibility in the design of programs and use of federal funds. This allows each state to make its own decisions about eligibility and services provided for the waiver. Medicaid waiver programs are usually administered through a state's department of health, department of human services, or a similar agency.

To apply for a waiver program, an application must be filed with the state agency that administers the program. Often supporting documentation will be required such as medical records to prove the disability and financial records to prove financial eligibility.

- **Intellectual/Developmental Disability Waiver (I/DD Waiver)**
    - May be part of the Home and Community Based Waivers system;
    - Usually under the state's Medicaid umbrella so benefits may be dramatically different from state to state;
    - Usually provides supports to individuals with a qualifying intellectual or developmental disability;
    - Supports may include:
        1. Physical therapy;
        2. Occupational therapy;
        3. Speech therapy;
        4. Assistive technology;
        5. Home modifications;
        6. Home healthcare;
        7. Case management services;
        8. Supported living; family living; independent living;
        9. Community supports services (sometimes known as "day hab"); and
        10. Supported employment services.
    - The I/DD Waiver may also provide necessary items such as incontinence supplies, oxygen, feeding supplies;
    - The I/DD Waiver is typically not a cash program;
    - Those eligible for the I/DD Waiver usually will also receive Medicaid as their health insurance program to cover the costs of doctor's visits, hospitalizations, and medications;
    - Many states have waiting lists of months or years for the allocation of services; and
    - Eligibility is typically based upon the Social Security standard for "disability" along with a financial eligibility requirement.

Social Security: SSI and SSDI

These benefits are received directly from the federal government through the Social Security Administration. If an individual is under the age of 18, the income of the entire household (i.e., the parents or guardians) is counted toward determining financial eligibility through a concept called "deeming." If an individual is 18 years or older, only their income is counted toward determining financial eligibility.

Applications for these benefits are submitted through the Social Security Administration's website. Documentation to prove the disability and financial eligibility will be required.

Supplemental Security Income (SSI)

SSI is a cash program. Every eligible individual receives the same amount of money each month regardless of the nature of the qualifying disability, the level of their needs, and the city and state in which they reside. Eligibility for SSI:

- Over age 65; or blind or disabled;
- Limited income and resources;
- U.S. citizen or national, or in one of certain categories of aliens;
- Resident of one of the 50 states, the District of Columbia, or the Northern Mariana Islands; and
- Is not confined to an institution (such as a hospital or prison) at the government's expense.

What does "disabled" mean for SSI purposes?

- For those under age 18, there must be a medically determinable physical or mental impairment, (including an emotional or learning problem) that:
  - results in marked and severe functional limitations; and
  - can be expected to result in death; or
  - has lasted or can be expected to last for a continuous period of not less than 12 months.
- For those over age 18, there must be a medically determinable physical or mental impairment (including an emotional or learning problem) that:
  - results in the inability to engage in substantial gainful activity; and
  - can be expected to result in death; or
  - has lasted or can be expected to last for a continuous period of not less than 12 months.
- What is considered "income"?
  - Money earned from work;
  - Money received from other sources, such as Social Security benefits, workers compensation, unemployment benefits, the Department of Veterans Affairs, friends, or relatives; and
  - Free food or shelter.
- What is considered a "resource"?
  - Cash;
  - Bank accounts;
  - Stocks, mutual funds, and U.S. savings bonds;
  - Land;
  - Vehicles;
  - Personal property;
  - Life insurance; and
  - Anything else that the applicant owns that could be converted to cash and used for food or shelter.

Social Security Disability Income (SSDI)

The SSDI program pays cash benefits to the eligible worker and certain family members if the worker is "insured." This means that the worker worked enough quarters – and recently enough – and paid Social Security taxes on their earnings. The amount is based upon the number of "work credits" the worker has prior to becoming disabled. Eligibility for SSDI:

- Have worked in jobs covered by Social Security; and
- Have a medical condition that meets Social Security's definition of disability.
- There is no resource limit for receiving SSDI.

Disabled Adult Child (DAC):

Another type of SSDI benefit is called Disabled Adult Child benefits. An adult who has a disability that began before age 22 may be eligible for benefits if their parent is deceased or starts receiving retirement or disability benefits. Social Security considers this a "child's" benefit because it is paid on a parent's Social Security earnings record.

For any type of Social Security benefit, a Representative Payee may be appointed to manage the benefits if the Social Security Administration determined that the beneficiary is not able to do so themselves. See Section 6 below for more information about Representative Payees.

Vocational Rehabilitation ("Vocational Rehab" or "VR")

What Is VR?

- Vocational Rehabilitation is the primary public program to support people with disabilities to achieve competitive employment outcomes.
- This program is usually run through the state government and may be a part of the state's education department, human services department employment division, or social services department.
- Often this service can be started when a person is in high school and by contacting the state vocational rehabilitation office.

Who is Eligible?

- An individual who has a physical, mental, emotional, or learning disability that is a barrier to the individual getting and keeping a job, including services to prepare the individual to get, keep, or regain employment.

Is VR Required for Everyone with a Disability?

- Before a VR agency can determine that an individual cannot benefit from VR services, it must explore the individual's work potential through a variety of assessments and trial work experiences. Trial work experiences might include supported employment or on-the-job training in realistic work situations. The trial work experiences must:
    - Be in competitive, integrated employment settings to the maximum extent appropriate;
    - Be of sufficient variety and over a sufficient length of time to determine whether the individual can benefit from services; and,
    - Provide support (such as assistive technology and personal assistance services).

VR for Students

- Additional school-to-work transition services called "Pre-Employment Transition Services" (Pre-ETS) are provided by VR agencies to students with disabilities while they are still in secondary school. Pre-ETS do not require VR eligibility determination.

Care Management for the Special Needs Child Whether a Minor or Adult

Ensuring proper in-home support is critical. This includes the following:

- Support that is properly trained for the child's needs so that parents have the personal and physical assistance they need to maintain full-time care;
- Ensuring all eligible waivers are applied for to facilitate funding for support; and,
- Additional activities, such as day programs, classes, and other resources are available.

It's important to create a transition plan for the adult child who lives at home but will need a new arrangement once parents are no longer able to provide the care, due to their own disability or death.

- If the hope is that the child moves in with another family member, is that plan feasible? Who will pay for it? How will the move happen logistically? Who will provide care in the interim until the move can occur?
- If a group home or assisted living facility is necessary, how will it be paid for? Have parents or guardians toured and selected a facility? Is the child on waitlists in the appropriate state?
- What support does the child need – emotionally, mentally, and physically – while the plan is being implemented?
- In what state is all this happening? If the child is moving to a new state, what benefits will be maintained, what will need to be applied for, and how long is the transition or waiting period in between?
- Also, see Section 5, below/Living Arrangements.

4 Transitions for School and Work

Extended Education/School Year ("ESY")

What is ESY?

Extended school year (ESY) services are special education and related services that are provided to a student with a disability beyond the regular school year in accordance with the child's Individualized Education Program (IEP). The need for ESY services must be determined annually on an individual basis by the individualized education program (IEP) team.

Who is eligible?

Eligibility for ESY services is assessed by a student's IEP team. An IEP or special education services in school do not automatically make the child eligible for ESY. Eligibility varies by school district and/or state and must be determined by the child's IEP team annually. Parents can request an ESY program through the child's school district or at the next IEP meeting. Similar to other decisions made by the school district, if a child is denied ESY services, the parent can appeal.

The two most common factors reviewed for determining eligibility for ESY are regression and recoupment. Is the child at risk of regressing – losing skills and knowledge – during a break from school? The IEP team will also look at recoupment – how long it might take for the child to regain the skills and knowledge they may have lost over the break. If the summer break or school vacation is likely to lead to a significant regression in the progress the child has been making, and/or if the child's progress will be significantly delayed when the break is over, the school will determine what services may be required to prevent that from happening.

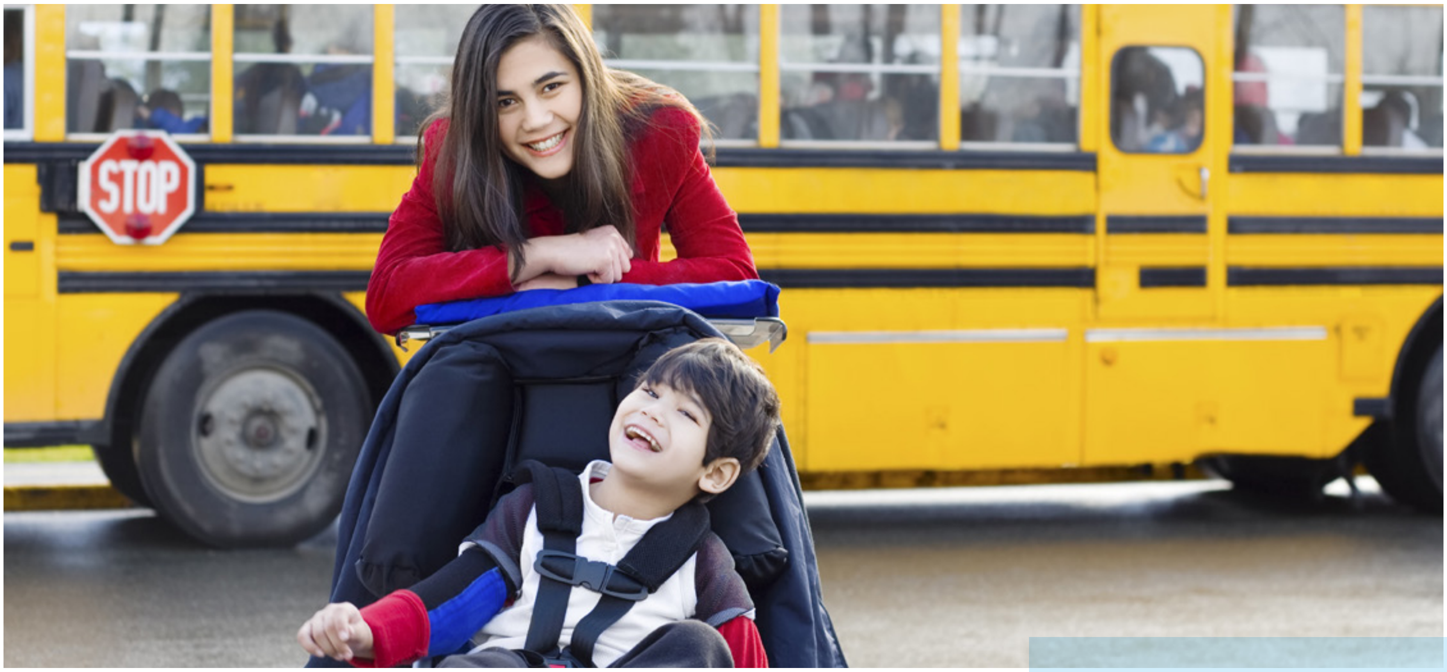
Other factors may include:

- If the student is close to a breakthrough in learning;
- If progress has stalled toward a specific IEP goal; and,
- If the child needs to continue learning a critical skill related to self-sufficiency and independence.

Supported Employment

What is Supported Employment?

Supported employment refers to services for obtaining and maintaining employment for people with disabilities, including intellectual disabilities, mental health, and traumatic brain injury, among others. Supported employment is considered to be one form of employment in which wages are expected, together with benefits from an employer in a competitive workplace, though some versions refer to disability agency paid employment.



What are the key features of Supported Employment?

- Lend competence to the individual with disabilities until they learn the job.
- Be accountable for facilitating job opportunities.
- Target jobs that individuals with disabilities may not otherwise have knowledge of access.

What else is important to know?

- A supported employee can be the only employee with a disability in an organization.
- A supported employment setting cannot have more than six employees using supported employment services.
- A supported employee can be self-employed in their own business.

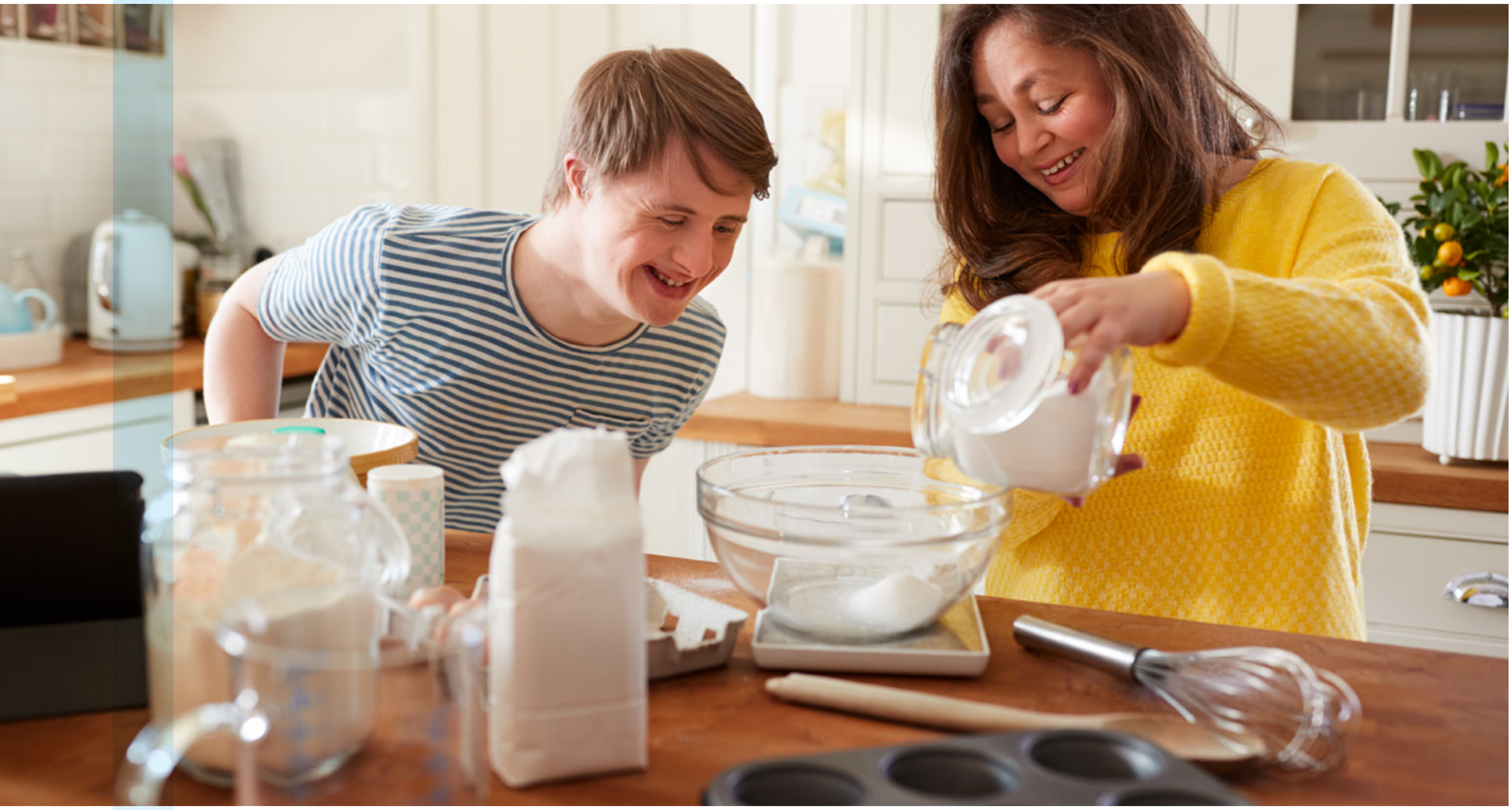
How does it work?

A vocational rehabilitation counselor works with the individual to formulate a plan for supported employment. As part of the planning process, the individual can select a community-based service provider from those available in the community. Services provided by the selected community-based service provider included a vocational evaluation, job development, and job coaching. Funding begins with the vocational rehabilitation program and then is picked up by the state developmental disability agency at the time period designated in the supported employment plan.

What is Day Habilitation?

Day Habilitation is a service that supports individuals with intellectual and developmental disabilities who need help acquiring, retaining, or improving socialization and adaptive skills to improve their community experience, as well as the experience of other members of the community. Day habilitation participants learn new skills and achieve greater independence.

5 Living Arrangements



Finding suitable housing and living arrangements for an individual with disabilities is often a high priority for the individual and their family. Yet, finding an appropriate and affordable arrangement can be a significant challenge, especially if the individual needs on-site support and financial assistance from government programs or private funds. Many of the aspects of living arrangements, such as decision-making authority and public assistance programs are discussed in prior sections of this handbook.

Types of housing and living arrangements available to individuals with disabilities include the following:

- **Supported Living/Group Homes:** Supported Living Services (SLS) provides people with developmental disabilities with support in home and in the communities where they live. With this service, people live in a home with other individuals who have intellectual or developmental disabilities. The home has around-the-clock staff to provide assistance, support, and safety for the residents.
- **Independent Living**: Provides support and services for individuals with I/DD so that they can live independently in their own home without 24/7 support.
- **Family Living**: Provides the opportunity to live in a typical family setting when residential habilitation is needed. Services and support are provided by a natural family member, host family member, or companion.

6 Financial Arrangements

SNT

- A special needs trust (SNT) is a trust that will preserve the beneficiary's eligibility for needs-based government benefits, such as Medicaid and Supplemental Security Income (SSI). Because the beneficiary does not own the assets in the trust, he or she will be eligible for benefit programs that have an asset limit. As a general rule, the trustee will use trust assets to supplement the beneficiary's government benefits but not replace them. Examples of supplemental needs are costs for sitters, companions, and dental or medical expenses not covered by Medicare or Medicaid. In many cases, the SNT will provide for payment of activities and expenses that provide a better quality of life for the beneficiary, such as paying for social events, leisure travel, and hobbies.
- A complete description of the types, features, and uses of SNTs is beyond the scope of this handbook, so please refer to other numerous resources regarding special needs trusts offered by the Special Needs Alliance and consult with a Special Needs Alliance member attorney for advice about your particular circumstances.

ABLE

What is an ABLE account?

- Created by the 2014 ABLE Act (Achieving a Better Life Experience Act), ABLE accounts are tax-advantaged savings accounts for individuals with disabilities and their families. The beneficiary of the account is the account owner, and income earned by the account is not taxed.
- Contributions to the account, which can be made by any person (the account beneficiary, family, friends, special needs trust) must be made using post-tax dollars and will not be tax deductible for purposes of federal taxes; however, some states may allow for state income tax deductions for contributions made to an ABLE account.

Why are ABLE accounts needed?

- Individuals with disabilities and their families often depend on a wide variety of public benefits for income, healthcare, and food and housing assistance. Financial eligibility for many of these public benefits restricts individuals to $2,000 in countable resources, such as non-ABLE checking and savings accounts and some retirement accounts.
- To maintain eligibility for these public benefits, an individual must remain under the resource limit. The ABLE Act recognizes the extra and significant costs of living with a disability, including accessible housing and transportation, personal assistance services, assistive technology, and healthcare not covered by insurance, Medicaid, or Medicare.
- Eligible individuals and their families can establish ABLE accounts that will not affect their eligibility for SSI, Medicaid, and means-tested programs.

Who is eligible for an ABLE account?

- An individual is eligible for an ABLE account if their disability begins before age 26. Effective January 1, 2026, an individual whose disability began before age 46 can establish an ABLE account. If someone meets this age requirement and is also receiving benefits under SSI and/or SSDI, they are automatically eligible to establish an ABLE account.
- If the beneficiary is not a recipient of SSI and/or SSDI but still meets the age of onset disability requirement, they are eligible if they meet Social Security's definition and criteria regarding functional limitations and receive a letter of disability certification from a qualified healthcare provider, such as a licensed physician.
- To establish an ABLE account, the beneficiary does not need to be younger than the eligibility age at the time the account is created. Rather, the eligibility age relates to the onset of the disability, even if the ABLE account is established years, or even decades, after the disability began.

What are the limits on an ABLE account?

- The total annual contributions to an ABLE account from all sources are limited to the annual gift tax exclusion amount. (For 2023, that amount is $17,000.) Certain additional amounts may be deposited if the account beneficiary has earned income.
- The total lifetime limit is the state's limit for education-related 529 savings accounts, which range from approximately $250,000 to $550,000. However, for individuals who receive SSI, the ABLE Act limit is $100,000.
    - If an ABLE account balance, when combined with other resources, exceeds $100,000, the beneficiary's SSI cash benefit is suspended. When resources return below $100,000, benefits are reinstated without a time limit.
    - While the beneficiary's eligibility for the SSI cash benefit is suspended, they remain eligible for medical assistance through Medicaid.

What else do I need to know about ABLE accounts?

- Each eligible beneficiary is limited to only one ABLE account.
- An ABLE account may be used for a "qualified disability expense," which may include education, food, housing, transportation, employment training and support, assistive technology, personal support services, healthcare expenses, financial management and administrative services and other expenses which help improve health, independence, and/or quality of life.
- Any funds remaining in an ABLE account at the beneficiary's death may be subject to reimbursement to states' Medicaid programs as payback for Medicaid benefits the beneficiary received after establishment of the ABLE account. This payback requirement is an important consideration for individuals other than the beneficiary who wish to contribute to an ABLE account. (Although payback or recovery from a beneficiary's trust or estate is common in most state's Medicaid programs, some states currently do not seek payback from ABLE accounts.)
- An eligible beneficiary may open an ABLE account in any state that has an ABLE program, so long as the program accepts out-of-state beneficiaries.
- An ABLE account may provide more choice and control for the beneficiary and their family than a special needs trust. The cost of establishing an account will likely be considerably less than establishing a special needs trust. The ABLE account owner controls the account, versus a trustee managing a special needs trust. In many cases, an ABLE account is a significant and viable option in addition to, rather than instead of, a special needs trust. Determining which options and combinations are most appropriate will depend upon individual circumstances.

Social Security Representative Payee

For any type of Social Security benefit, the Social Security Administration may appoint a Representative Payee to manage the beneficiary's Social Security benefits, if the Social Security Administration determined that the beneficiary is not able to do so themselves.

Who may be the Payee?

- A representative payee can be a person or an organization.

How does someone get appointed as a Rep Payee?

- The Social Security Administration appoints a payee to receive the Social Security or SSI benefits for anyone who can't manage or direct the management of his or her benefits.

What are the duties of a Rep payee?

- A payee's main duties are to use the benefits to pay for the current and future needs of the beneficiary, and properly save any benefits not needed to meet current needs. A payee must also keep records of expenses. A Rep Payee must provide an annual accounting to the Social Security Administration of how he or she used or saved the benefits.

Is a Rep Payee the same as a POA?

- Being an authorized representative, having power of attorney, or a joint bank account with the beneficiary is not the same as being a payee. These arrangements do not give legal authority to negotiate and manage a beneficiary's Social Security and/or SSI benefits. To be a Pre Payee, an individual must apply for and be appointed by the Social Security Administration.

7

Additional Resources

Special Needs Alliance: www.specialneedsalliance.org

Social Security Administration: www.ssa.gov

National Guardianship Association: www.guardianship.org

ABLE National Resource Center: www.ablenrc.org

US Department of Education: www.ed.gov

Local Department of Health, Medicaid Services Department