

**Special Needs Planning –  
What is it and where to start?**

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## **Resource:**

For learning more about special needs planning, and the use of special needs trusts:

**Special Needs Alliance:** <https://www.specialneedsalliance.org>

## **Introduction to special needs planning:**

What the heck is a “special need”?

According to the Merriam-Webster dictionary, it means “any of various difficulties (such as a physical, emotional, behavioral, or learning disability or impairment) that causes an individual to require additional or specialized services or accommodations”.

We all have difficulties, and at some point in our lives we all require additional or specialized services or accommodations (rehab, physical therapy, counseling, tutoring, service animals). Typically, these needs don’t rise to a level requiring comprehensive planning. But for those who do have special needs, planning can make a real and significant change in the quality of life they enjoy.

Any of these conditions may call for special needs planning:

1. Dementia and cognitive decline
2. Major physical disabilities (e.g., quadriplegia, blindness, ALS, Parkinson’s)
3. Developmental disabilities (e.g., autism, Down Syndrome)
4. Substance abuse
5. Mental illness

Various public benefits and programs may be available for any of these populations. Special needs planning can help enhance the beneficiary’s living arrangement while not jeopardizing those (actual or potential) benefits. Of course, even when public benefits are not in issue, special needs planning can help provide management and protection for vulnerable or incapable beneficiaries.

Sidenote: “Special needs” and “supplemental needs” are sometimes used interchangeably. This can be confusing. Supplemental needs are the “non-basic” needs that are not provided for by government benefit programs. Supplemental needs typically include most needs other than food or shelter, such as hobbies, travel, household extras, but can include some medical care not provided for through benefits. But there is no widely-recognized distinction between plans or documents described by one term or the other – or any of several other popular variants, for that matter.

## **Organizing the Planning:**

To start, it’s important to get a complete picture of the individual’s circumstances. Circumstances such as age (minors, young adults, seniors) and current housing arrangements (houseless whether by choice or not, group homes, IDLA, etc.), medical and daily physical care

needs, and family involvement, are crucial for crafting a plan. Also critically important: understanding the current public benefits profile of the beneficiary.

### **Housing arrangements:**

Typical housing arrangements for individuals with special needs include:

1. Family arrangements – many people live with their families.
2. Group Homes: Group homes are residential facilities that provide housing and support services for people with disabilities. These homes typically house a small number of residents, and staff members provide assistance with daily living activities, such as cooking, cleaning, and personal care. Group homes can be a good option for people who need more support than they can receive in their own homes, but who do not require 24-hour medical care.
3. Assisted Living Facilities: Assisted living facilities are similar to group homes in that they provide housing and support services for people with disabilities. However, they are typically larger and provide more extensive services, including 24-hour nursing care, medication management, and rehabilitation services. Assisted living facilities can be a good option for people who require more medical care than they can receive in a group home.
4. IDLA- Independent Living: Independent living options provide people with disabilities the opportunity to live on their own in a self-contained unit or apartment. These units are designed to be accessible and may include features such as grab bars, wheelchair ramps, and wider doorways. Independent living can be a good option for people who are able to live on their own but need some support, such as transportation or assistance with daily living activities.
5. In-Home Care: In-home care provides people with disabilities with support services in their own homes. These services can include assistance with personal care, medication management, and housekeeping. In-home care can be a good option for people who want to remain in their own homes but need some support to do so.
6. Skilled Nursing Facilities: Skilled nursing facilities provide 24-hour medical care and rehabilitation services for people with disabilities. These facilities are typically larger and more institutional than other housing options, and may be a good option for people who require extensive medical care.

### **Medical care and assistance with daily living:**

At the heart of planning for a person with special needs is the necessity to provide medical care and assistance with daily living. This is utterly important, and there is no template. Each individual is unique, and their needs will likely change over time.

The medical care can sometimes be extraordinary (e.g. dialysis, frequent hospitalizations, constant monitoring with breathing support, skin breakdown), but sometimes it is no more than an average individual's care (e.g. a young, healthy person with Down Syndrome).

Assistance with daily living is generally the most expensive item. The choices regarding care providers are complex and we won't cover them here. It is necessary to know the cost of the care

in order to make a plan for covering that cost. The process is sometimes interactive, in that the available programs to cover the costs may dictate the choice of care.

The role of agencies in providing the care is worth mentioning here. The government benefits provide the funds with which to pay for the care, and the individual or their agent has choices regarding which agency to use. Families often misunderstand this, thinking that the government is deciding on the agency for them, or that they cannot request a change if the care is subpar.

### **Financial resources:**

Identifying the financial resources in a picture is necessary. In doing so, we have to look at both current and future scenarios.

Earned income is sometimes a factor. Individuals with disabilities can be earning, and sometimes the amounts are substantial. Benefits provided by an employer, such as medical insurance and life insurance, can be helpful. However, awareness that these benefits are tied to the employment and would cease if the individual can no longer work requires a backup plan.

Employment options include supported work programs (Beacon Group, DES). Some agencies provide support for employment of individuals with disabilities, providing transportation, training, and counseling.

Earned income can negatively impact eligibility for certain benefits, such as social security, SSI, section 8 vouchers, etc.

Very often, government benefits provide the bulk of the income needed for basic food and shelter. Sustaining eligibility for these benefits comprises much of the planning in a special needs situation. Assessing the eligibility for these benefits and assisting in application for them is a valuable service. Locating a specialist for some applications may be necessary, such as social security disability, where applications are routinely denied.

The process of determining financial resources also involves taking a look at the individual's extended family. Possibly, assets to fund a trust are coming from someone other than the individual, or a family member intends to include the individual in their estate plan or make gifts. Sometimes family members are providing basic support, which they may not be in a position to continue indefinitely.

Estate planning can be relevant if the family resources are significant. Even in families with lesser assets, planning related to retirement accounts can help maximize the assets.

Liabilities are an issue, too. An individual with a disability may have incurred debts in trying to cope with their situation, or may be liable for back taxes, child support, or other liabilities. One common concern: family support that everyone thinks of as loans against a future date when more funds will become available, but which were not documented contemporaneously.

### **History:**

Collecting some information about the individual's personal history can help in the planning. Details about their families, when and how they became disabled, their prior employment, previous marriages, military service, skills, and other personal factors can affect available

resources and options. So do family dynamics, religious preferences, alternative lifestyle and care choices.

### **Teamwork:**

An individual with special needs benefits from a team concept when it comes to planning. If they are fortunate enough to have caring family members or close friends, these people are an important part of the planning process. Also, having legal, tax, financial, and fiduciary team members is generally essential. Each plan is unique to the circumstances and needs of the individual. Providing the full complement of skills on the team helps achieve the best result. It's not an area of practice for the lone wolf.

Often, family involvement is integral to planning. Families frequently provide physical, emotional, and financial support, as well as serving in a fiduciary or trust protector role.

However, families are sometimes not in agreement about these roles, and can have unrealistic expectations. An aging family member may refuse to acknowledge that they will not be able to continue to maintain a household. A family member who is not even able to adequately manage their own financial affairs may want to handle the financial matters. Helping to sort this out and reach reasonable, sustainable plans for the roles that the family will serve in the plan is a valuable service that the advisors can provide.

Sometimes, it is necessary and /or desirable to compensate the family members for the roles that they fill. This is an emotionally charged area, and another place where the professional advisors can help.

### **Trustees/POAs/Guardians:**

1. Trusted family friends
2. Siblings
3. Parents or grandparents
4. Children
5. Professional fiduciaries
6. Trust companies
7. Private fiduciaries (a category, incidentally, that is both licensed and prevalent in Arizona but scarce in some other states and completely missing in still others)
8. Law and accounting firms (though note that in Arizona, most professional firms acting as fiduciary will necessarily also qualify as private fiduciaries)

### **Financial advisors:**

The ideal financial professional for a special needs plan combines investment management with the ability to help with budgeting and other types of financial decisions. Questions often arise regarding all types of insurance (medical, life, homeowners), as well as larger expenditures such as home improvements. These decisions have to be made in the context and constraints of a long-term care management plan. The financial management should maximize the individual's life experience while ensuring financial security. Conflicts can arise. Risk management is important. It's not an easy task, and a good financial advisor can make a big difference in the outcome of the long-term plan.

Family members will sometimes want to avoid the added expense of a financial advisor by managing the assets themselves. Unless they are themselves trained in this field, that's usually a

bad idea because they will generally manage the assets the same way they manage their own assets and that probably won't be appropriate for the situation.

If appropriate for the circumstances, the financial advisor will also be involved in the use of ABLÉ accounts, and in the planning for any distributions from retirement accounts.

### **Legal matters:**

People with special needs can have all the same legal needs as people without special needs. They may need legal advice related to wills, divorce, adoption, criminal matters, and civil disputes. They are also likely to need legal advice related to eligibility for government benefits, advice regarding supplemental needs trusts, and specialized estate and trust services. They are more likely to need an ongoing relationship with an attorney.

### **Tax and accounting matters:**

If an individual with a disability is the beneficiary of a supplemental needs trust, they may need accounting services related to reporting the income from the trust. They, or their families, may also need advice related to the deduction of medical expenses, determining dependency exemptions, gift and estate tax reporting, and fiduciary accountings.

## **Government Benefits:**

Government benefits can be divided into two broad categories: those that are means-tested for eligibility, and those that are not. This is a hugely significant initial issue to resolve in each case. A non-means-tested benefit will continue to be available even if the beneficiary receives funds directly, or a special needs trust makes direct distributions that would cause problems for a means-tested benefit. The most common benefits to consider (and a little information about eligibility and special concerns):

### **Non-means-tested benefits**

**Social Security Disability Insurance** (SSDI or, sometimes, SSD) – provides monthly income to those who have participated in the Social Security program and who is or has become disabled. “Disability” for this program means that the participant must be “unable to perform any substantial gainful activity” because of a disabling condition. “Substantial gainful activity” is defined as the ability to earn at least \$1,470/month (the 2023 figure for non-blind applicants). Note that SSDI is available to spouses and dependent children (including adult children) of the wage earner in at least some circumstances. So a 30-year-old developmentally disabled adult who was diagnosed before age 22 is likely to be eligible for some SSDI benefits on his parents’ Social Security account – though not until they begin receiving Social Security retirement or disability benefits (or they die).

**Medicare** – a federal health care program providing benefits to those over age 65 (regardless of their normal retirement age for Social Security purposes, or their retirement status) or those who have been on SSDI for at least twenty-four months. Medicare coverage is pretty broad, though it does not include any significant long-term or personal care. There are also co-payments, deductibles and premiums associated with Medicare, though there are several ways those costs can be minimized or eliminated in at least some cases.

### **Means-tested benefits**

**Supplemental Security Income (SSI)** – provides monthly income to anyone who is age 65 or older, blind, or disabled, and has limited income and limited assets. For disabled applicants, the definition of disability is identical to the SSDI definition described above. The financial eligibility limits (there are lots of exceptions and qualifications here, so be aware that this is an over-broad generalization): an applicant must have less than \$2,000 of “available” resources (not counting a home, vehicle and household effects) and income of less than the maximum federal SSI benefit (\$914 in 2023). Some states – but not Arizona – provide supplements to that maximum federal figure.

**Medicaid** – provides health coverage to low-income adults, children, and people with disabilities. Medicaid is funded jointly by the states and the federal government. In Arizona, Medicaid is administered through the Arizona Health Care Cost Containment System (AHCCCS).

**AHCCCS** – there are actually about eight different programs that fit under the AHCCCS umbrella. The most important ones provide general medical care (there is no asset limitation for this program, and income eligibility can be calculated under any of several different methods) and long-term care. The long-term care program is relevant to those in nursing care (though some of those participants are actually at home, or in group homes or assisted living facilities), those with developmental disabilities, and the seriously mentally ill. Those three populations are all served through the Arizona Long Term Care System (ALTCS), a subdivision of AHCCCS

**ALTCS** – unlike the relative generosity of the general AHCCCS/Medicaid benefit, the ALTCS benefit can be very difficult to navigate. It has both income and asset limitations. The asset eligibility requirements are borrowed from SSI (see above), with a very different and much more complicated approach for married couples where one spouse is seeking benefits. The income limit is more generous than the SSI benefit, but calculated somewhat similarly. Income eligibility is keyed to the maximum SSI benefit, but is set at 300% of that figure (so, for 2023, \$2742). For married couples, the income limit can be calculated either by adding all income to either spouse and halving the result, or considering only the income paid to the institutionalized spouse.

**Section 8 housing vouchers** – provides housing subsidies paid directly to the landlords. To qualify for a Section 8 housing choice voucher, a household must make a gross (total) income below 50% of the median for their area. Increased (or imputed) income doesn't always knock the participant off the program, but the participant is required to pay 30% of their income toward their rent (the program subsidizes the balance), so income received by a participant can increase their rent.

**Veterans Administration** – provides medical care, long-term care for disabled veterans and, in some cases, assistance with long-term care needs for a veteran's surviving spouse.

**Supplemental Nutrition Assistance Program (SNAP)** – The old “food stamp” program is run by the states but funded by the federal government. It is income-tested, and is based on the Federal Poverty Guidelines for the community and household size. In 2023 in Arizona, a family of four must have income below \$2,312; a married couple's income must be less than \$1,526. The amount of the benefit also depends on family size.

**Temporary Assistance for Needy Families (TANF)** – this cash subsidy, also called Cash Assistance in Arizona, is based on both income and asset eligibility and is limited both by time and willingness to seek work.

## **Other Available Resources:**

Community resources

1. Disability Benefits 101 ([www.az.db101.org](http://www.az.db101.org)) is a terrific resource to help navigate eligibility programs
2. Veterans Administration
3. Department of Economic Security (their website, at <https://des.az.gov>, is actually pretty helpful for a lot of topics)
4. Habitat for Humanity
5. Pima Council on Aging (there are few resources that can help with Medicare issues, particularly – area agencies on aging like PCOA are usually the best)
6. Agencies (Echoing Hope)
7. Pima County Developmental Disabilities Program
8. Southern Arizona Autism Association
9. Also see: Sonoran Center for Excellence in Disabilities - <https://sonorancenter.edu/resources/disability-organizations-and-agencies>
10. Information & Referral Services, Inc. - Information & Referral Line: (520) 881-1794

## **Creating the plan (team effort):**

1. Identify government benefits that are already in place or for which eligibility can be achieved. Assume that what the individual or family members tell you about program benefits will almost always be incomplete, slightly off or flat-out wrong.
2. Identify eligibility for any other programs; determine if they are needs-based. Has a parent begun receiving Social Security, or died? Reconsider benefits that might be available. Has the beneficiary been able to work part-time for some months or years? They might now qualify for part benefits on their own account.
3. Determine whether assets should be repositioned for preservation.
4. Review legal documents, determine if revisions/creation are necessary.
5. Make a budget for personal needs
6. Make a plan for asset investment

The steps are not sequential. Rather, each step helps inform the others, so that it is like solving a Rubik's cube. Changing one fact can open up or alter other opportunities. An open mind and willingness to rework, revisit, refresh helps get the best results.

## **Creating and Using Special Needs Trusts:**

The first division for special needs trust planning is to determine whether the beneficiary might need a first-party or third-party trust. Also in the mix: might a pooled special needs trust, or even a "Miller" trust, be appropriate? Let's start by trying to demystify those distinctions:



**Third-party special needs trust** – money that is not already available to the beneficiary might go into a third-party trust. This is the classic device that most family members should look to before leaving money directly to their child, grandchild or other family member with a disability. But be clear: a trust established by a parent but funded with money that belongs to the beneficiary is *never* a third-party trust. That is true even if the funds never actually reached the beneficiary (as, for instance, if the funding comes from a personal injury settlement of the beneficiary’s lawsuit).

A third-party special needs trust is a much more flexible animal than its first-party cousin. First, it need not have (and pretty much never should have) a payback provision. But also: it is not limited in the types of things it can be used for – though some kinds of distributions might affect the availability or the amount of public benefits.

What makes a given (third-party) trust a “special needs trust”? In Arizona, the answer is fairly straightforward (warning: some few other states have different notions about the answer to this question – notably Ohio, Missouri and Iowa). The trustee must have discretion as to both distributions of income and principal. Ideally, there will not be any easily-interpreted standard of distribution (like the classic “HEMS” standard), and certainly no reference to support or maintenance. If the trustee is given broad discretion and required to use it to enhance the happiness and autonomy of the beneficiary, that is almost certainly good enough. If the trust specifies that the trustee is to consider the availability of public benefits and the overall well-being of the beneficiary, so much the better.

Two things to look for in third-party trust language:

1. It would be nice NOT to have any language precluding distributions that affect public benefits. Sometimes, a thoughtful trustee might actually choose to disqualify the beneficiary (either permanently or for a period of time) in order to enhance their quality of life. Other times it might be appropriate to reduce the SSI benefit, for example, while providing better housing options for the beneficiary.
2. It would also be nice to have specific language authorizing the trustee to make distributions to an ABLE Act account for the beneficiary. Unless the language is uncommonly restrictive, such a distribution is probably permissible anyway. But a modern well-drafted third-party special needs trust should specifically include ABLE Act language. More about the usefulness of the ABLE Act is below.

**Self-settled special needs trust** – if an unrestricted inheritance comes to a person with special needs, or their personal injury lawsuit is settled – or they have accumulated wealth before seeking public benefits eligibility, for that matter – a self-settled trust may be appropriate. There are a number of specific things to consider (see 42 U.S.C. §1396p(d)(4)(A) for the precise requirements for a self-settled special needs trust, and A.R.S. §36-2934.01 for Arizona’s oddball, picky and probably impermissible additions to the federal requirements):

1. The trust must be established by one of a specific list of possibilities – the beneficiary him or herself, a parent or grandparent, a guardian (note that the Social Security Administration appears to believe that this can be a conservator in states like Arizona that use modern language) or a court. This requirement is much easier since the law was expanded to permit the beneficiary to act, but it still is limited to those individuals.

2. The trust must be established (and funded) before the beneficiary turns 65. Why? Because it says so. There's not really a good policy explanation for this, except perhaps that the Congress wanted to prevent people from sheltering assets and getting nursing home care. But if you need nursing home care before age 65, you're good.
3. The trust must include a payback provision. Arizona law mandates that Arizona must specifically be mentioned, and that no other state (or the possibility of other states) may be included. Federal law, meanwhile, requires that this provision include the possibility of proportional payback if multiple states are involved. How to resolve the difficulty? Largely by misdirection.
4. The public benefits recipient must be the *only* permissible beneficiary of the trust for their lifetime. The Social Security Administration has sometimes insisted that including a provision allowing the trustee to travel to visit the beneficiary, for instance, would be impermissible – because travel to visit your mentally-ill brother is, of course, for *your* benefit rather than his. While they have backed off on this particular item, it is illustrative of the SSA approach to these trusts: they assume that everyone involved in one is trying to scam the system and must be prevented from doing so.
5. There is much discussion about whether a self-settled special needs trust should include a “laundry list” of permissible uses. On one hand, it would be good to guide the trustee (who might be a clueless or even hapless family member) about ways in which the trust could be used. On the other hand, the trust's beneficiary might read the list as mandatory, and it could set up unnecessary conflict. And, finally, the public benefits agencies will also read the list, hoping to find something they could point to as an impermissible expenditure.
6. There can not be any early-termination provision, because the Social Security Administration believes that would allow someone other than the beneficiary to benefit from the trust. That makes no sense, and termination of small trusts is permissible under Arizona law (and the Uniform Trust Code) even if no provision is included, but there's no point in poking the bear on this one. Just keep repeating this mantra: the law students who got the highest score in their estate and trust classes seldom end up advising government benefits programs about how trusts work.
7. In Arizona, the ALTCS agency currently insists that the trust may not reimburse anyone for their expenditures on behalf of the beneficiary (because that would benefit the person receiving reimbursement, according to their twisted argument). That has been extended to prohibit even direct payments to the family member's credit card. So another arrangement has to be worked out to pay for ordinary types of things like medical supplies, travel and transportation.

There's more. Lots more. But that should give you a sense of the goofiness of self-settled trust drafting and administration.

**Pooled special needs trusts** – the same federal law that authorizes self-settled special needs trusts (well, two sub-sections below it, anyway) specifically authorizes pooled special needs trusts. There is a nationwide industry of pooled trusts, though they have not made much of an inroad in Arizona. These trusts must be administered by a non-profit (not necessarily a charitable organization). One other oddity in the federal law on these trusts (at 42 U.S.C.

§1396p(d)(4)(C)) is that the payback provision can instead provide that the remaining balance on death of a participant can be held by the non-profit for the benefit of others similarly situated. The Social Security Administration has interpreted that to mean that the money must stay in the master pooled trust, and be used only for other pooled trust participants. Some states have tried to argue that the payback must still be at least 50% to the state, but that's simply not what the federal law says.

**“Miller” trusts** – it's with great trepidation that we even list this commonly-misunderstood instrument. Authority for what is universally referred to as a Miller trust is shoehorned between the self-settled special needs trust and pooled trust sections of the federal law, at 42 U.S.C. §1396p(d)(4)(B). The Miller trust addresses one thing, and one thing only: what to do about a nursing home resident who makes more than the \$2742 income maximum (in 2023) but not enough to pay the \$5,000 - \$8,000 necessary to pay privately for long-term care? The answer is the magical Miller trust. But it solves exactly zero other problems, and there's no point in doing one (and in fact it might be detrimental) if the beneficiary is not otherwise eligible for ALTCS. It solves all ALTCS income-eligibility problems, which sounds good – but it is so misunderstood that it consumes way too much oxygen in this arena. Why doesn't Arizona join the 20+ states that just give up and don't impose an income cap? A cynic would argue that it must be because some small number of applicants never understand how easy it is to solve this problem, and family members either keep the patient at home after they need nursing home care, or they subsidize costs without ever applying for ALTCS. But surely the state would not use trickery to distract people from the benefits that they are entitled to receive, would they?

## **A Fuller Understanding of Special Needs Planning**

In order to help navigate the special needs arena, there are at least three concepts that need to be reviewed and elucidated. They arch over most of the other material here:

**The Program Operations Manual System (POMS)** – the Social Security Administration has long maintained a guidebook (it was once literally a book – now it's completely online, of course, at <https://secure.ssa.gov/apps10/>) for its eligibility workers. It is not statute, nor even regulation – but the federal courts have generally given some deference to the POMS (Cf. *Rose, as Next Friend of Rose v. Brown*, 14 F4th 1129 (Tenth Circ. 2021). The POMS subdivision on SSI benefits (and, to a lesser extent, the sections defining disability in the Disability Insurance subdivision) flesh out the rules and provide very precise requirements for some elements of the eligibility process. While the POMS explicitly apply to Social Security only, they often – but not always – have direct effect on the Medicaid rules that may depend on SSI eligibility.

**In-Kind Support and Maintenance (ISM)** – this is a uniquely SSI concept – it is not applied (at least not directly) to the other benefits programs. It is predicated on the SSI distinction between income (stuff you get this month – from whatever source) and assets (stuff you still have on the first day of next month). “Income” can include cash, cash-like things (such as gift cards or other things that can be turned into cash), things that can be converted into food or shelter (such as non-refundable gift cards for restaurants), and the direct provision of food and shelter.

An important aside: things that can't be turned into food or shelter, but that are directly provided by someone else, are NOT income. So, for instance, if your father pays your cable bill,

or your car insurance, that is not income. But if he gives you the money to pay your own cable bill or auto insurance, that is income – even if you do, in fact, pay those bills.

But back to the direct provision of food and/or shelter: the POMS spell out the penalty for such items, and it is not precisely intuitive. The POMS invoke what they call the “Presumed Maximum Value” rule (or, sometimes, the 1/3 reduction rule – but they amount to essentially the same thing). The presumed maximum value of the direct provision of food and/or shelter is the lesser of (1) the fair market value of the thing you have been given, or (2) one-third of the maximum federal benefit plus \$20.

Let’s try an example. Your father gives you \$1,000 to pay your rent, and you do. That was \$1,000 of income. But suppose your father pays your rent directly: that will amount to (in 2023)  $(\$914/3) + \$20$ , or \$324.67. That’s the amount by which your SSI check will be reduced.

Same result if your special needs trust pays your rent directly. Same result if a community fundraiser pays your rent. Same result if your father pays \$1,500 in rent. Same result, for that matter, if your father pays your \$1,500 rent AND goes to Safeway and buys you \$1,000 of groceries in that same month – multiple food/shelter items do not increase the penalty in a given month. But if your father pays your rent AND gives you \$1,000 to buy groceries (or a \$1,000 Safeway gift card), then your income for that month will be calculated as \$1,000 + \$324.67, or \$1,324.67.

This is why, by the way, so many SSI recipients receive a maximum of \$609. If they live at home and pay no room or board, the \$324.67 reduction is applied (and the result is rounded down to the nearest dollar). Those SSI recipients can immediately get raised back to the maximum figure by simply paying rent of, say, \$600/month to the parents with whom they live.

Note that only food and shelter count as ISM. And shelter is narrowly defined. It includes these items, and these items only (see POMS §SI 00835.465(D)):

1. Mortgage (including property insurance required by the mortgage holder)
2. Real property taxes (less any tax rebate/credit)
3. Rent
4. Heating fuel
5. Gas
6. Electricity
7. Water
8. Sewer
9. Garbage removal
10. Condominium fees, to the extent that they include water, sewer, garbage removal or other listed items

What’s often important about ISM is what’s *not* on the list. It doesn’t include homeowner’s insurance, new appliances, home repair, home improvement, or any non-home items. That means there’s no eligibility problem with paying for education, entertainment, travel, transportation, medical care or supplies, or any number of things. The trustee just can’t use cash (which does cause problems from time to time with recreational or even medical marijuana, or companionship).

**ABLE Act Accounts** – the Achieving a Better Life Experience (ABLE) Act was adopted in 2014 and has been amended a couple times since then. It permits states to create programs for

accounts that vaguely resemble 529 education accounts (and, in fact, the Internal Revenue Code section governing ABLE Act accounts is IRC §529A), and make them available to people with disabilities. The ABLE Act was initially intended as a substitute for special needs trusts, but that's not how they turned out. In fact, the accounts are a terrific supplement to special needs trusts in many cases. The rules are actually pretty straightforward, but there is a lot of misinformation and misunderstanding about the accounts and how they operate.

ABLE Act accounts are available to any person who receives SSI or SSDI (or would be eligible for either program but for resource or age limitations), but only if their disability onset was before age 26. Why 26? It was solely because that's what age the Congressional Budget Office set as revenue-neutral in return for removing ED drugs from Medicare coverage. The eligibility age is scheduled to increase to 46 in 2026 (numerologists might love the multiple 6s).

Arizona has adopted an ABLE Act program. More precisely, Arizona signed on to the Ohio plan, which is called STABLE. The Ohio program (and its ancillary programs in about a dozen states) is at this point the biggest ABLE Account program in the country.

One caveat: ABLE Act accounts must pay back their entire accumulated value to state Medicaid agencies at the death of the beneficiary – very much like self-settled special needs trusts. This means that they are not really suitable for substantial third-party contributions, unless the contributions are used on an ongoing basis. And, since the maximum annual contribution is \$17,000, they are not suitable vehicles to receive a parent's estate (or a share thereof) unless the estate is very small.

Any eligible disabled person may open an account in any of the states that have adopted a plan, regardless of where they live BUT each person can have just one account. All contributions to the account combined (including contributions by the disabled person themselves) may not exceed the maximum gift tax exclusion amount in a given year. So if an individual's mother contributes \$10,000 to an ABLE Act account for them, their grandfather is limited to \$7,000. And, if the mother and grandfather contribute a total of \$17,000, the person can not put any of their own money into the account – except that there is one special rule for a disabled person who is working (many beneficiaries have part-time jobs) but is not covered by their employer's retirement account.

Contributions to the account are not treated as income by the IRS or Social Security. Earnings inside the account are tax-free. Withdrawals or distributions from the account are never income for Social Security / SSI purposes, and are not taxable income so long as they are used for "Qualified Disability Expenses". The definition of QDEs is very broad, and it is likely that almost any distribution that one can imagine will qualify – but if one does not, the taxation is based on the annuity rules, so only the earnings inside the account are taxed. And, since the beneficiary is probably living on SSI or SSDI, it is extremely unlikely that they will pay any income tax on any distribution anyway. But to reiterate: even if the distribution has some taxation effect, it is still not income for Social Security purposes.

If the total value of the account exceeds \$100,000, the beneficiary's SSI benefits are suspended. But the statute is very clear that their Medicaid benefits are not. And the SSI is suspended, not lost; as soon as the account is brought down below \$100,000 again, SSI resumes. And, since the accounts have limited contributions and have only been around for about six years, there simply aren't any \$100,000 accounts anyway. Yet.

The comparison to §529 accounts is intentional but differs in subtle ways. One important one: while a 529 account still belongs to the owner who contributed the money, the ABLE Act account conceptually belongs to the disabled beneficiary. Though a parent can open the account for the disabled person, it is the beneficiary's money, not the parent's.

The maximum contributions to the account are keyed to the state's maximum §529 contributions. Accounts can be moved from one state's program to another, but a new account can not be opened up for someone who already has an account.

So how are ABLE Act accounts such game-changers? They have proven to be extremely useful in these situations:

1. Enhancing autonomy. Because one option in the STABLE program (and a number of the other state programs) is to give the beneficiary a debit card, this can allow them the freedom of having spending cash that does not mess up their eligibility. This can be a terrific benefit for the highly functional but disabled beneficiary who has had to focus on staying below \$2,000 of available resources since their initial eligibility application.
2. Rent. Review the calculation above about ISM, and the illustration about paying rent and suffering a reduction in SSI income. Now consider the ABLE approach. If dad puts \$1,000/month in the ABLE Act account, disabled daughter can use it to pay all or a portion of her rent with NO effect on her SSI benefit. And it's the same result if a special needs trust makes the \$1,000/month contribution. Of course, with a \$17,000/year limitation, it's hard to get to \$1,500/month in rent subsidy. But still.
3. Marijuana, companionship, alternative therapies (is any of this redundant?). This can be the way that a disabled person can get resources to pay for things that are both difficult to do with a credit card and subject to societal or parental opprobrium.
4. Reimbursements. As indicated above, ALTCS (but not SSA) takes the view that a special needs trust cannot reimburse a parent or other person for payments already made on the beneficiary's behalf. But because ALTCS has no say on ABLE Act disbursements, in some cases this can make it easier to reimburse legitimate expenses for things like medical supplies and therapy payments. ALTCS has recently begun to acknowledge that they have no business even asking about ABLE Act expenditures, so that holds promise for the future use in this manner.

### **“Income,” “Income” and “Income”**

Most people who work in both the trust and tax worlds have managed to grasp the distinction between trust accounting income and taxable income. Now to introduce a third kind of income: benefits eligibility income.

Because self-settled trusts are always grantor trusts, income to the trust is imputed to the beneficiary. Even for third-party trusts, taxable trust income may pass through to the beneficiary based on (entirely permissible) direct payments for the benefit of the beneficiary. Tax practitioners, especially, often worry about the possibility that income reported on the beneficiary's 1040 might cause problems with their public benefits eligibility.

The concern is not misguided. SSI and Medicaid programs both eventually get taxable income information, and in the past eligibility workers have been known to have problems with public benefits recipients who have substantial taxable income. The good news: the notion that public benefits income is not the same as taxable income has taken hold in the benefits programs and is usually understood by eligibility workers. Not always, but usually.

One particular problem does sometime surface, though. As indicated above, one of the several Medicaid/AHCCCS programs is based on the applicant's Modified Adjusted Gross Income, or MAGI. When trust DNI appears on the taxpayer's 1040, it might actually knock them off AHCCCS in such a case. While that seems like an obvious problem, however, it has not proven to be much of a problem in the real world. Most people for whom it might be an issue tend to be so seriously disabled that they are eligible for ALTCS benefits (which does not look at MAGI). Still, it can be an issue; it might well cause the trustee to reconsider investment choices to reduce the likelihood of a problem going forward.

## **Using retirement plans in special needs planning:**

Providing for a person with disability is much more easily accomplished in a family with a lot of assets. In those circumstances the job is to choose the among the available assets for the best ones to use. A more challenging circumstance is when the assets are fewer and there is a retirement plan that will necessarily provide some (or in some cases, all) of the funding for the special needs trust.

The reason that a retirement plan is a difficult asset to use in special needs trusts is that the income tax on retirement plan distributions is significant. A trust funded with a \$2m IRA has a very different financial picture than one funded with perhaps \$2m of (tax-free) life insurance proceeds. Given that a trust can be subject to up to 40.8% federal income tax as well as state income tax, and that in a third party special needs trust any income not distributed to the beneficiary will be taxed at the trust level, the trust funded with a retirement plan may ultimately be able to provide only about half as much support to the beneficiary as the trust funded with the life insurance.

Getting retirement accounts into the trust can be tricky. This generally occurs when the trust inherits a retirement account. Transferring the inherited retirement account to the trust must be done carefully to ensure that the initial transfer isn't taxed as a distribution of the entire account.

If the SNT is a third-party SNT, then the retirement account being received by the trust is likely coming from the estate of the grantor. This would occur when the special needs trust has been designated as a beneficiary of the retirement plan, or when the executor of the estate has chosen to transfer the retirement plan to the trust as part of the trust's share of the decedent's estate. The trust then holds an inherited retirement account (generally an IRA) and is subject to tax on the distributions from the IRA. The required minimum distribution (RMD) rules for inherited IRAs apply.

The RMD rules become really important in this situation, because if the money comes out of the IRA slowly, it's likely that it can be used for the needs of the beneficiary as it comes out, thereby moving all the taxable income to the beneficiary where it will likely be taxed at a low rate. If the beneficiary has significant medical expenses, the IRA distributions may even be sheltered by those deductions. Conversely, if the money comes out too quickly and can't be used for the

needs of the beneficiary, the taxable income is trapped at the trust level and subjected to higher tax rates.

So, it's important to determine the RMD, and generally favorable if the RMD can be based on the life expectancy of the beneficiary. This can be achieved in a special need trust if the trust is a "see-through" trust, and the beneficiary is an Eligible Designated Beneficiary (EDB).

First, a quick review of the rules. Under SECURE, almost all beneficiaries of IRAs, 401(k)s and other retirement assets must withdraw all of the assets by the year containing the tenth anniversary of the owner's death. But a trust for a beneficiary with a disability OR a chronically ill beneficiary is treated more favorably. Those two categories (along with three others) can be Eligible Designated Beneficiaries, or EDBs, and get to use their own life expectancy calculations for scheduling withdrawals.

Under SECURE, a see-through accumulation trust (STAT) for the benefit of a disabled (or chronically ill) EDB *is* entitled to the EDB treatment/life expectancy payout—even though see-through accumulation trusts for other categories of EDB are not so entitled. SECURE calls this an "Applicable multi-beneficiary trust" (AMBT).

And, by the way, it might be worth considering whether most disabled beneficiaries might not also be chronically ill within the meaning of the SECURE Act. In four of the five EDB categories, if the beneficiary ceases to qualify he or she has a new 10-year distribution period from the date of non-qualification. So, it's worth discussing whether a given beneficiary's disability is more likely to resolve than their chronic illness, or whether continued chronic illness will be easier to establish than continued disability.

But enough about that interesting aside. One other practical effect of the SECURE rules was to fundamentally shift the conversation with clients about funding sources for their special needs trusts.

For example, under the old rules it was often true that beneficiaries with disabilities were more likely to need to withdraw funds more quickly than other potential beneficiaries. And the tax effect for a disabled beneficiary might well be harsher, since a trust for their benefit would necessarily be an accumulation trust. So, the value *to the beneficiary* of a retirement account might be greater to a non-disabled beneficiary (and particularly to one who did not have particularly high earnings). Of course, it was often true that the disabled beneficiary, likely to have a much lower tax bracket and high annual needs, might be the "better" beneficiary of a retirement account.

But with SECURE, it will likely more often be true that the disabled/chronically ill beneficiary is better-served by having retirement accounts assigned to "their" trust share. They will be the only members of the client's family (well, discounting spouses) who can get a long-lasting stretch of the retirement asset. That, coupled with their likely lower tax effect, will most often make the retirement account a more valuable benefit to the disabled beneficiary than to the non-disabled beneficiary. Of course, the accumulation trust's higher tax liability might still reduce that benefit – but the much-lower annual withdrawal amounts will often compensate for that difference.

Consider this illustration:



Client Carol (age 65) has an estate of about \$3 million, conveniently divided into approximately-equal shares of a \$1 million IRA, \$1 million in investment assets, and a \$1 million home. She has three children: Sam is 40 and receives SSI benefits, Deborah is 42 and works as an investment banker, and Terry lives with Carol and is 45 and is a long-haul trucker.

If Carol makes Sam's SNT beneficiary of her IRA, the trust will have to take about 2½% of the trust principal out each year for the next several years (increasing, obviously, pretty quickly). Meanwhile, Carol might want to leave her home to Terry (after considering how Terry is going to be able to maintain such a valuable house, considering taxes, upkeep and insurance). And the stepped-up basis might make the other investment assets attractive to Deborah.

Note, though, that if Carol seeks to reach parity (or fairness, or equal distribution, or however she views the division), then she has to acknowledge that the value *to each beneficiary* of each of her asset classes differs. Not only is there tax liability to consider, but also the growth potential, effect on lifestyle and resolution of problems (or creation of new problems) for each beneficiary.

Of course, what most clients ultimately do is to simply divide each asset class equally among their children. But what an opportunity for added value to help Carol work through this analysis. Oh, and when you explain to Carol that (since Sam first started receiving SSI benefits at age 18), when she finally starts receiving Social Security benefits herself, Sam's Dependent Adult Child benefits might actually knock him off SSI and move his medical care to Medicare – you have definitely added value to the consultation.

Some retirement plan transfers can't avoid taxation. This comes up sometimes when a disabled individual funds a first party special needs trust. If the beneficiary has a retirement plan account that is standing in the way of the beneficiary's eligibility for benefits, liquidating the account and paying the tax may be a necessary move. Then the net proceeds can be transferred to the first-party trust. It's not something to do without considering all the other options first.

## **Miscellaneous tax matters:**

### Medical expenses:

In the case of individuals with special needs, medical expenses may be incurred for a variety of reasons, including medical care, therapy, medications, and assistive devices. These expenses can add up quickly and can be a significant financial burden for families. However, if the individual is not claimed as a dependent on the taxpayer's tax return, the expenses may still be deductible if the taxpayer provides more than half of the individual's support. This can sometimes ease that burden significantly.

For example, if a parent provides more than half of the support for their adult child with special needs who is not claimed as a dependent on their tax return, the parent may still be able to deduct the medical expenses incurred for their child if they exceed the 10% AGI threshold.

### Dependent Care Credits:

A sometimes overlooked source of help is the dependent care credit. If the disabled individual is a dependent of a person who is employed (e.g. a spouse with early onset Alzheimers) and care is needed for the time when the person is at work, there is a tax credit available for a percentage of

the cost of care. This credit is widely used for the care of young children and nicknamed the “child care credit”, it can sometimes be missed when the care is of an older person.

## **Special situations:**

### Rental of residence:

Often, the Supplemental Needs Trust (SNT) will own the home in which the beneficiary lives. Sometimes other family members also live in the home, and they may pay rent (or not). Sometimes, a portion of the home is rented to other people, usually people with disabilities who are also eligible for Medicaid. (AHCCCS).

It’s worth observing that parents (particularly, but not solely) often have unrealistic expectations about how their home will be used after their death. They may observe that their child with a disability has lived in the same house for most of their life, and would be most comfortable staying in the same place. But the foothills home with three bedrooms and an expansive common area will likely be completely unsuitable for a sole resident with a disability – even with a full-time resident caregiver. And the costs associated with that home may be a serious drain on the special needs trust’s income or even principal. A fixation on using that home might also increase the costs of care, if it requires full-time nursing service care that could be better provided in a shared living arrangement in a purpose-built home.

All of that said, it can sometimes work well to have a shared residence in the family home. One benefit for the child whose trust owns the home: if there are personality problems, or family changes, the trust beneficiary is not likely to be the one who has to move out of the house. So, let’s assume that there is a house (either the parent’s house, a house they bought expressly for the disabled child, or a house purchased by the special needs trust for this purpose) being used as a shared rental with one or more tenants in addition to the trust beneficiary.

The portion of the home being rented for full value to the unrelated parties will be reportable on Schedule E. The expenses of the home that are allocable to the rented areas (using a reasonable method, usually by square footage) are allowable as expenses, and a net loss is allowable, subject to the passive activity loss rules.

The portion of the home that is rented to family members is also reportable on Schedule E, and allocable expenses, including depreciation, are allowable up to the amount of the rental income. Losses in excess of rental income are disallowed under section 280A, so this portion can never report a loss. Suspended losses can be carried forward to use against future income from the property.

The expenses allocable to the portion of the home used by the trust beneficiary or family members at no charge are not deductible, except for the mortgage interest and real estate taxes.

Expenses allocable to the common areas of the home are not deductible because the common area is not used exclusively for rental purposes. Likewise, yard maintenance is not deductible.

### Family as employees of the SNT:

The care required by a person with chronic illness or disability can be overwhelming. The burden often falls on family members, who may find it difficult to work and provide care. Some families make the decision to have family members (frequently the mother) provide care in

place of or together with professional care providers. The SNT can hire the family caregiver to provide this care.

As the SNT is solely for the benefit of the disabled person, the trustee must be careful to determine reasonable compensation for the family care provider.

As an employer, the SNT will be subject to employment taxes. If the SNT is a third-party trust it can file Schedule H and pay the payroll taxes with its income tax return. If a first-party trust, the Schedule H will be filed with the beneficiary's individual tax return. State unemployment tax returns will also be required if the compensation exceeds \$1,000 per quarter.

If the care provided to the beneficiary meets the criteria for a medical deduction, it may arguably be deducted on the beneficiary's individual tax return, even though it was paid by the SNT (Lang v. Comm TCM 2010-286). Where wages are deductible as medical expenses, the associated employer payroll taxes are also deductible. The IRS may object to the medical deduction of expenses paid by a third party SNT on the grounds that the expenses were not paid by the individual taxpayer. In Lang, the court ruled that the payment of medical expenses by a parent as a gift to the daughter were deductible by the daughter because the substance of the transaction was a gift from the mother with which the daughter paid her own medical expenses. In the trust context, a distribution for the benefit of a beneficiary is essentially a cash distribution (gift) from the grantor of the trust, which is then used to pay the expense.

#### Caregiver issues:

Caregiver issues can arise. A common issue is a long-term care provider who refuses to provide information needed for the issuance of form W-2. Caregivers occasionally exercise undue influence to request gifts or loans, and theft sometimes occurs. These issues can be minimized or at least handled more professionally if the care providers are hired through reputable care agencies. Care agencies can also provide case managers who can help determine the appropriate level of care.

#### Vulnerability to influence:

Vulnerability to influence is not unique to people with disabilities. It can occur and be exploited in any demographic. However, people with disabilities are more susceptible in general because they are often physically dependent on their care providers, and they may also be overly reliant on other advisors. If a person with disabilities has an ethical and competent fiduciary, they have some protection.

One group that is perhaps even more at risk are the "undiagnosed". Hard to describe, but you know them when you encounter them, these people have usually been sheltered into adulthood by their families, without any formal acknowledgement of disability. Indeed, they are sometimes extremely intelligent although not independent. Left to fend for themselves when their parents pass on, they become targets for the societal vultures that seek out the vulnerable. Standard inheritance trusts under which the beneficiary serves as his or her own trustee are not adequate protection. Special needs trusts are not the right solution here, either. These individuals might benefit from a trust with a professional trustee or co-trustee that can only be removed and replaced by an independent trust protector who knows the beneficiary pretty well. Finding that person can be a challenge.

## **Case studies:**

### Case Study One:

Young family with a disabled child, moderate resources, other children, some limited extended family assets (grandparents):

Until the child reaches age 18 they aren't eligible for SSI or SSDI, but may be eligible for educational assistance (early preschool, one-on-one classroom aid). Caregivers and respite care may be provided through ALTCS. The family may qualify for AHCCCS.

Consider connecting the family with local organizations that support people with the child's specific disability.

Consider a life insurance policy to fund the SNT, and funding an ABLÉ account. If assets were already placed in the child's name (UTMA), consider how to use these funds to minimize interference with other benefits.

Review legal documents to ensure appropriate guardianship for all the children, wills, maybe establishment of a SNT for assets that may be directed to it in the future. The choice of fiduciary will be very important given the responsibility of minor children. It may be necessary to coordinate with extended family members (e.g. grandparents) to plan for passage of assets so that their estate plans don't upend the special needs planning.

Help the family make a budget. Is their income adequate, or are they falling into debt?

Consider care options – will both parents be able to continue working?

Make a plan that provides for preservation of parental assets in protected vehicles (ERISA plans, home equity, life insurance), funding of college accounts for the other children.

### Case Study Two:

Older couple with savings, all community property, serious long-term disability developing in one spouse.

Identify government benefits that are already in place or for which eligibility can be achieved. Consider whether the disabled spouse may qualify for VA assistance or other benefits associated with prior employment or union status. Will eligibility for ALTCS be achievable? Would a Miller Trust help?

Review any long-term care insurance to see how it will fit in.

Connect them with the Pima Council on Aging and other support groups.

Determine whether the nondisabled spouse's separate property can be segregated, and review what assets exceed the Community Spouse Resource Deduction (currently \$148,620). Remember that the nondisabled spouse could become disabled or die. Are current expenses being taken from accounts which need to be spent down?

Review legal documents to ensure the wills, trust document (if any), health care directives, and powers of attorney are up to date. Consider divorce (pretty radical)?

Make a budget for personal needs – is the income adequate for increasing care costs; if not, what is the projected deficit and how soon?

Consider care options – can the disabled individual participate in the choices?

Make a plan for asset investment – preservation of community or joint assets in protected vehicles (ERISA plans, home equity, life insurance), reposition liquid assets for anticipated needs.

### Case Study Three:

Young adult with lawsuit settlement, may be married, needs long-term care but has some limited capability for potential employment.

Identify government benefits that are already in place or for which eligibility can be achieved. Will eligibility for ALTCS be necessary currently or in the future? Is SSI/SSDI available? Medicaid or Medicare? Was the disability the result of military service?

Identify eligibility for any other programs; determine if they are needs-based – connection with local organizations with support groups might be of benefit. The disabled spouse may have employer or union benefits.

Determine whether assets should be repositioned for preservation – can the spouse's separate property be identified and segregated? Are current expenses being taken from accounts which may need to be spent down?

Review legal documents, determine if revisions/creation are necessary – first party SNT? Post marital agreement for protection of spouse's property?

Make a budget for personal needs – will the long-term care needs be stable, or likely to change? Is the income adequate for current needs? Does the individual anticipate (or already have) children?

Make a plan for asset investment – preservation of community or joint assets in protected vehicles (ERISA plans, home equity, life insurance), balance the need to protect the spouse's separate assets with the protection of the individual in case of divorce. Think REALLY long-term.

### Case Study Four:

Adult with serious mental illness, fluctuating abilities, may have some legal issues (minor infractions connected with periods of illness)

Determine if the individual is autonomous or is under a guardianship/conservatorship. Determine whether the individual can participate in the planning process.

Identify government benefits that are already in place or for which eligibility can be achieved. Will eligibility for ALTCS be necessary currently or in the future? Is SSI/SSDI available? Medicaid or Medicare? Any military benefits?

Connect the family with local support groups (although they probably already will be), like the National Alliance on Mental Illness (NAMI).

If the individual has any assets, determine whether they can be repositioned for preservation. Are current expenses being taken from accounts which may need to be spent down?

Review legal documents, considering a first party SNT, will, health care directive, power of attorney. For adults with family involvement, parental/extended family involvement and document review.

Make a budget for personal needs – will the long-term care needs be stable, or likely to change? Is the income adequate for current needs? Does the individual anticipate (or already have) children?

Make a plan for asset investment – this can be really difficult with a long-term serious mental illness because the needs can fluctuate greatly, and the individual’s ability to participate in the planning can be variable.

### Case Study Five:

Young to middle aged adult with no known diagnosis, but still living with or dependent on parents (failure to launch or return to the nest)

Determine if the individual is autonomous or is under a guardianship/conservatorship. Determine whether the individual can participate in the planning process.

Consider whether a medical diagnosis should be sought. Parents sometimes try to protect their child by avoiding the “label” of a diagnosis, not realizing that in the long term this may deprive the child of much needed benefits. Identify government benefits for which eligibility might be achieved if the most likely medical diagnosis were to be made.

Review legal documents, considering a contingent SNT, will, health care directive, power of attorney.

Make a budget for personal needs – will the long-term needs be stable, or likely to change? Is the income adequate for current needs?

Make a plan for asset investment. Consider life insurance on the parents if they are insurable (perhaps a second to die policy).

Consider vulnerability issues. If the child is being sheltered by the parents, they may be vulnerable to unethical advisors or others after the parents are gone. Consider naming a trustee or co-trustee if this is a likely threat. In cases of relatively minor family assets this may need to be another family member, if one is available and willing (although family members have been known to make bad trustees in some cases).

## **Conclusions:**

You can help your clients by engaging in special needs planning. A team approach gets the best results. The details are tricky, but can be navigated. The best solutions available today may not be the best answers for tomorrow. Periodic reassessment of the planning is crucial to being situated optimally “when the music stops”.