

ABLE Accounts, Special Needs Trusts, and Lifetime Financial Planning

A simple guide for families

Use public benefits and private money together. Build a plan for the child's full lifetime. Prepare the work yourself, then pay professionals only for the judgment and review that truly require them.

Final edition

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Prepared with AI assistance.

Booklet + companion Lifetime Planner

This booklet's mission. Help families spend *less* on planning. Then more money is left for their child with a disability. At the same time, protect three things: the parents' money for old age, the family's way of life, and the cost of therapies the person needs right now. Every chapter serves this mission.

Please read this first. This booklet teaches. It is not legal advice. It is not tax advice. It is not investment advice. It cannot take the place of your own papers — most of all your trust papers. The rules here are federal rules as we know them in 2026. Dollar amounts change each year. States run Medicaid in their own way. When this booklet talks about a choice you must make, it ends with a flag. The flag tells you which expert to ask. Use those flags.

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Editions. This is the October 11, 2026 edition. Dollar limits change each year. For the newest edition and any corrections, search this booklet's title online or write to the contact above.

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The free companion **Lifetime Planner** workbook — the spreadsheet that models a child's lifetime year by year — travels with this booklet's download page. If you received a forwarded copy, search this booklet's title online to find the newest edition and the workbook.

Chapter 1 — How to Use This Booklet

You may be a parent, grandparent, brother, sister, or friend of a person with a disability. Or you may one day be in charge of a special needs trust. You want to help with money. You do not want to harm the government help your loved one gets. This booklet is for you.

Why These Tools Exist

Programs like SSI and Medicaid give monthly money and health care. But they have strict limits. A person can only have so much income and savings. A kind gift can push a person over the limit. Then they lose their benefits. An inheritance left in the wrong way can do the same.

Over the years, Congress made special tools. These tools let families save and give *without* taking benefits away. The two most important tools are:

- **ABLE accounts** — savings accounts owned by the person with a disability. They have special shields against benefit limits.
- **Special needs trusts (SNTs)** — a legal setup where a manager holds money for the person. Rules keep the benefits safe.

This booklet tells you how each tool works. It tells you how they work together. It tells you how to plan for a whole lifetime. It tells you how taxes work. It tells you how to keep the tax bill as low as the law allows.

The Mission: More Money for Your Child, Less Money Spent Getting There

This booklet has one job. **Help families spend less on planning, so more money is left for their child with a disability.** Three things must stay safe at the same time:

1. **The parents' old-age money.** The plan must not leave the parents broke. That helps no one.
2. **The family's way of life.** Brothers, sisters, and the home have needs too. The plan must be honest about hard choices.
3. **Therapies needed now.** The person may need therapies today. Those costs cannot wait for a thirty-year plan.

Chapter 8 shows this mission in action. It shows how to do homework yourself. You fill in the *Lifetime Planner* workbook. You write a letter of intent. You gather your papers. You write your questions. Then a costly full-service job becomes a much cheaper *review*. Each hour you prepare is an hour you do not have to buy.

Key Words, Up Front

You will see these words a lot. Here is what they mean:

- **Beneficiary** — the person the money is for. Your loved one with a disability.
- **Trustee** — the person or company in charge of a trust. They manage the money and choose how to spend it.
- **Grantor** — the person who makes the trust and puts money in it.
- **Principal** — the main money in a trust. Not the earnings. The main pile.
- **Distribution** — a payment from a trust or account, to the person or for the person.

More words are in Appendix A.

How to Read the "Confirm" Flags

At the end of most chapters you will see a flag like this:

CONFIRM: **Ask your lawyer or tax expert before you act on this chapter.**

These flags matter. In special-needs planning, a small mistake can cost months of benefits. Or thousands in taxes. A wrong check. A payment at the wrong time. This booklet helps you ask good questions. The experts give answers for your case.

What This Booklet Does Not Do

It does not tell you what to do with your money. It does not read your trust papers for you. Only your trust papers — and the lawyer who wrote them — can do that. It does not cover every state rule. When your state matters, the booklet says so. It tells you where to check.

Chapter 2 — The Big Picture: Benefits and Private Money Together

First, see the whole land. Then the tools will make sense. A special-needs money plan has two kinds of money: **public benefits** and **private money**. The whole game is making them work together.

The Public Benefits

Supplemental Security Income (SSI). SSI is a monthly federal payment. It goes to people who are aged, blind, or disabled *and* have low income and low savings. One person can have no more than **\$2,000** in countable savings. That number has not changed since 1989. The government checks savings at the first moment of each month. Over the limit at that moment? No SSI that month. (Many people worry: the SSI payment itself lands near the 1st. Does it count against you? No. Money that comes in *during* a month is judged as income first. It only counts as savings if it is still there on the first of the *next* month.) SSI also has strict income rules. Money coming in can shrink the monthly check.

Social Security Disability Insurance (SSDI) and Disabled Adult Child (DAC) benefits. These are based on work records. They are not based on need. DAC benefits go to an adult who became disabled before age 22, is generally unmarried, and whose parent is deceased or gets retirement or disability benefits. They are based on a parent's work record. Some people call them Childhood Disability Benefits. They do not have the \$2,000 savings limit. But they mix with SSI. DAC money can shrink or replace SSI. One protection to know: certain former SSI recipients can keep Medicaid when DAC entitlement or an increase in DAC is what ends SSI, as long as they meet the other applicable requirements. Ask a benefits expert to confirm it for your case. That is why you must plan them together.

Medicaid. Medicaid is health coverage. Each state runs it under federal rules. For many people with big disabilities, Medicaid is the most valuable benefit of all. It pays for care that private insurance often does not. Like SSI, it is needs-based. Each state sets its own income and savings tests.

The Core Rule

One sentence runs this whole booklet:

Private money should add to public benefits. It should not replace them or copy them.

"Add to" means paying for what benefits do not fully cover. A nicer apartment in a safer area. Therapies insurance will not pay for. A computer. A trip. A paid helper. "Replace" would mean handing over cash that just takes the place of the SSI check. "Copy" would mean paying for what Medicaid already pays for. That wastes money. Every tool in this booklet keeps private money in the "add to" lane.

A Map of the Tools

Tool	In one sentence	Best for
ABLE account	A savings account owned by the person with a disability. Shielded from benefit limits up to \$100,000	Day-to-day spending; smaller savings
Third-party special needs trust	A trust funded with family money. A trustee manages it for the person	Large gifts and inheritances; long-term care of money
First-party special needs trust	A trust funded with the person's <i>own</i> money, like a court settlement	Shielding the person's own money; the state must be paid back at death
Pooled special needs trust	A trust run by a nonprofit. Many people each have their own part	Smaller amounts; no family trustee ready

Chapters 3 through 6 take each tool apart. The short version: most families use an ABLE account *and* a third-party trust together. Each does what it does best.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Benefits Checklist* sheet — go through the 14 life-event rows so you know which benefit events to watch for. PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Wage Log* sheet — if your loved one works, start logging pay months and SSA reports now. This chapter's SSI income rules are why it matters.

CONFIRM: **Ask a special-needs lawyer** before you pick tools for your family. The right mix depends on which benefits your loved one gets and how much money is involved.

Chapter 3 — ABLE Accounts: The Rules

An ABLE account is a savings account for people with disabilities. Congress made it in 2014. Think of it like a 529 college savings account. But it is for disability costs, not school tuition. The owner is the person with a disability. The account can pay for many needs without harming benefits.

Who Can Have One

Two paths. You need only one:

1. **Getting SSI or SSDI** for blindness or disability, or
2. **A doctor's note** saying the person has a lasting physical or mental problem that greatly limits daily life. It must be expected to last at least a year.

The disability must have started before a cutoff age. It used to be 26. **On January 1, 2026, the cutoff rose to 46.** Now millions more people can have ABLE accounts. This includes adults whose disability began in their twenties, thirties, or early forties. The cutoff is about when the disability *began*. Not how old the person is now.

Putting Money In: How Much, From Whom

- **Anyone can put money in** — the owner, parents, grandparents, friends.
- **One account per person** in the whole country.
- **2026 limit: \$20,000** per year, from all givers added together. This limit used to match the federal gift-tax limit. But a 2025 law (OBBA) changed the math for ABLE accounts only. So for 2026 the ABLE limit is \$20,000. The gift-tax limit stayed at \$19,000. (IRS Rev. Proc. 2025-32, §3.34.) Ask your state's ABLE program for the current year's number before you put money in.
- **ABLE to Work:** if the owner has a job and no work retirement plan, they can add *extra* money from their own pay. Up to \$15,650 for 2026 in most states. This number changes each year. Ask your state's ABLE program for the current figure.
- **529-to-ABLE moves:** money can move from a 529 college account into the ABLE account. No tax, no fine. But the moved money still counts toward that year's \$20,000 limit.

What the Money Can Pay For

Money taken out is tax-free when used for **approved disability costs**. The list is wide on purpose:

- Housing and living costs
- School and job training
- Rides and cars, including car changes for disability
- Health and wellness
- Tech aids and personal helpers
- Job support
- Money help, lawyer fees, and office costs

One warning needs its own space: **housing**. Housing is an approved cost. But SSI has a special timing rule after money leaves the ABLE account. If an ABLE withdrawal for housing is still unspent at the start of the next month, Social Security can count it as a resource. Plan housing withdrawals so the bill is paid in the same month as the withdrawal, and keep proof of the payment. Families trip on this often. If SSI is in the picture, ask the ABLE program or a benefits lawyer if the timing is not clear.

Money taken out for *other* costs is taxed. The growth part also gets a 10% fine.

The Tax Deal

Simple and good. You get no federal tax break for putting money in. (Some states give one — ask yours.) But **growth is tax-free, and approved-cost withdrawals are tax-free**. You file no yearly tax return for the ABLE account.

How ABLE Mixes With Benefits — The Part That Matters Most

- **SSI**: the first **\$100,000** in an ABLE account does not count toward the \$2,000 limit. Only the amount *above* \$100,000 counts. If that pushes total countable savings over the limit, SSI checks **pause** — but they are not ended. When the balance falls back down, checks start again with no new application. (Medicaid can carry on during the pause under its own rules — ask about your state's handling.)
- **Medicaid and other federal programs** (like housing help and SNAP food help): ABLE money does not count. No \$100,000 cap.
- **FAFSA**: ABLE money does not count for student aid.

What Happens to the ABLE Account at Death — It Differs by State

Federal law *lets* a state ask to be paid back from leftover ABLE money after the owner dies. But it does not *make* states do it. Many states have said no. California, Oregon, Pennsylvania, Virginia, Maryland, Ohio, and Illinois are some that have waived it or banned it. Other states still keep the right. Most ABLE programs take people from other states. So families in a payback state sometimes shop around — but be clear on what shopping can and cannot do: **opening an account in another state does not by itself stop your own state from making a claim** if your state paid for Medicaid. The state that paid is the state that can ask. Read your own state's papers first. And ask a lawyer, since rules keep changing.

Opening and Running an Account

States run ABLE programs. Most take people from other states. You open online. You do not send medical proof up front. But keep your proof handy — benefit records or the doctor's note — in case you are asked. You can pick how to invest, from safe savings to stock funds.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Parent Inputs* sheet. Fill in the ABLE part (starting balance, growth, spending, state cap) to see how ABLE fits your lifetime plan.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Benefits Checklist* sheet — check the ABLE rows (money in, housing money out) before you move money.

CONFIRM: **Ask the ABLE program — and, if SSI is involved, a benefits lawyer** — before big deposits or housing payments. Deposit-room math and housing timing are where families stumble most.

Sources: IRS Publication 907; SSA POMS SI 01130.740; 26 U.S.C. § 529A.

Chapter 4 — Third-Party Special Needs Trusts: The Rules

If ABLE is the spending wallet, a **third-party special needs trust (SNT)** is the vault. It is a legal setup. A person (the grantor) puts money or property with a trustee. The trustee uses it for a person with a disability (the beneficiary). The terms keep government benefits safe.

The One Question That Defines It: Whose Money Is It?

How a trust is treated comes down to one test: **whose money went in**.

- Money from *someone else* — parents, grandparents, an aunt, a life insurance check — makes a **third-party** trust.
- Money that belongs to the *person* — a court settlement, back benefits, an inheritance left in their name — makes a **first-party** trust.

This chapter is about third-party trusts. Most families make this kind. (First-party trusts are in Chapter 5.)

Why Families Use Them

A third-party SNT can hold any amount — \$50,000 or \$5 million. It does not count as the person's savings for SSI or Medicaid. Why? The money does not belong to the person. It belongs to the trust. The trustee chooses how to spend it. The person cannot demand the money. So benefit programs do not count it.

No Medicaid Payback

This is the part families love most. When the person dies, leftover money goes where the trust papers say — to brothers, sisters, grandchildren, a charity. The state gets nothing. This is federal law. It is the same in every state. No state can force payback on a well-made third-party SNT. The money was never the person's. (First-party trusts differ: federal law says they must pay Medicaid back first. That was the price Congress set for shielding a person's *own* money — see Chapter 5.)

Making and Funding the Trust

- **When:** a third-party trust can be made at any time, at any age. For a child or decades later.
- **Two kinds:** a *living* trust made now, or a *will* trust made through your will that starts when you die. Many families do both. The living trust takes gifts during life. The will trust is the backup.
- **Where money comes from:** lifetime gifts, wills, life insurance with the trust named, and retirement accounts (these need careful planning — see Chapter 7). A tax trap to know: the \$19,000-per-person yearly gift-tax break (for 2026) usually does **not** cover gifts into a trust, because trust gifts are often future interests, not present-interest gifts. The CPA must run the gift-tax math on trust gifts — a gift-tax return (Form 709) can be due even when no gift tax is owed.

"Extra Help" vs. "Must Support" — Why the Words Matter

Trust papers use one of two ideas. The difference is real:

- An **"extra help"** trust says the trustee *may* pay for extras *beyond* what benefits cover. It should avoid paying for what benefits already pay for.
- A **"must support"** trust says the trustee *shall* pay for the person's support. These words can make the trust money count for benefits.

Lawyers write third-party SNTs with "extra help" words. They give the trustee **full choice** over payments. That choice is the legal shield. No one can force the trustee to hand over money. So the money is not the person's savings.

Payment Rules and What They Do to Benefits

The trustee's spending choices affect benefits. The broad SSA rules:

- **Cash paid straight to the person** counts as income. It can shrink SSI.
- **Payments the trustee makes straight to sellers** (the landlord, the dentist, the computer store) are mostly *not* income. One big exception:
- **Seller-paid housing** — rent, house payments, property tax, lights and water — can count as **help with housing**. SSI may shrink the check by a capped amount. Since late 2024, food no longer counts in this rule — only housing does. (Cash handed over for food is a different story: cash can still count as income.)
- **Many seller-paid non-housing goods and services** — medical care, school, rides, fun, equipment — are not income at all.
- **Moves from the SNT to the person's ABLE account** do not count as income. This is one of the cleanest ways to get spending money to the person.

The pattern: the trustee should usually pay sellers directly. Be careful with housing. Send flexible spending money through the ABLE account. (Chapter 6 puts it all together.)

The Trustee's Job

Being a trustee is a real job with legal duties:

1. **Follow the trust papers first.** They are the instruction book. They beat everything in this booklet.
2. **Keep benefit rules in mind** for every payment — SSI, Medicaid, and state programs.
3. **Keep notes** on every choice: what was asked, why it was approved, how it was paid, what benefit check was done. (Chapter 11 gives you a system.)
4. **Never mix** trust money with your own money. Separate accounts, always.
5. **Invest wisely** and file the trust's tax returns (Chapter 9).

Picking Trustees — and Backups

This choice deserves as much thought as the money. The trust may run for decades after you are gone. Options:

- **A family member** who knows and loves the person. Plus: personal care. Risk: may lack money or benefits know-how, and may not outlive the person.
- **A professional trustee** — a bank trust office or trust company. Plus: skill and staying power. Cost: fees, and less personal warmth.
- **Co-trustees** — a family member plus a pro, splitting the personal and money jobs.
- **An advisory group** — friends and family who know the person well. They advise the trustee on life choices (a wheelchair van, a companion trip). They hold no legal power.

Name **backup trustees** in the papers. Name backups for the backups. A trust with no trustee is a crisis.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Parent Inputs* sheet — enter the SNT part (starting balance, funding amount and year, growth guesses) to model the trust's lifetime growth. PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Advisor & Sources* sheet — use the trust-wording questions when you meet the lawyer who will write the papers.

CONFIRM: **Ask a special-needs lawyer** before making, funding, or changing a trust — and before any odd payment. The trust papers rule; this chapter teaches the ideas behind them.

Sources: SSA POMS SI 01120.201; the governing trust document.

Chapter 5 — First-Party and Pooled Trusts: How They Differ

Chapter 4 covered trusts funded with *other people's* money. This chapter covers the other two kinds. These use the **person's own money**, or are run for many people together.

First-Party Special Needs Trusts

Sometimes the person's *own* money needs shielding. A car-crash settlement. Saved-up back benefits. An inheritance someone wrongly left to them outright. (That last one is a painful, common mistake — which is why Chapter 7 says wills should pour into a third-party trust instead.)

Congress made a path for this. Lawyers call it a "(d)(4)(A) trust." The rules:

- It must be set up **before the person turns 65**.
- The person must meet the disability test.
- **Medicaid payback is a must.** When the person dies, the state is paid back first from what is left, for Medicaid it paid. Only then does anything go to heirs.
- For income tax, it is usually a **grantor trust** — the person pays the tax, not the trust. (Chapter 9 tells what that means.)

The payback is real. But keep it in view: without the trust, the money would have killed benefits right away. Payback at death is the price of shielding the money during life.

Pooled Special Needs Trusts

A **pooled trust** is run by a nonprofit group. Many people each have their own part. The nonprofit manages and invests all the money together. Federal law allows this.

One age warning: federal law sets no age limit to *join* a pooled trust. But putting the person's *own* money in at age 65 or older can trigger a Medicaid transfer penalty. Timing matters — get advice before funding at 65 or older.

Pooled trusts fit when:

- The amount is too small to pay a lawyer for a standalone trust.
- No family member can or should be trustee.
- You want a pro who knows benefits, without hiring a bank.

When the person dies, leftover money is usually **kept by the nonprofit** to help others. But federal law still requires Medicaid to be paid back first from any amount the nonprofit does not keep. Some trusts and some states handle the split differently. Read the nonprofit's master papers with care.

Side-by-Side Look

	Third-party SNT	First-party (d)(4)(A) SNT	Pooled trust
Whose money	Family / others	The person's own	The person's own (some programs take family money too)
Medicaid payback	None	Must pay back	Nonprofit usually keeps its share; Medicaid is paid first from the rest
Age limit to make	None	Before age 65	None to join — but funding at 65 or older can trigger a transfer penalty
Usual tax setup	Trust pays its own tax	Person pays the tax	Varies; read the papers
Trustee	Picked by the family	Picked by the family	The nonprofit group
Fits when	Gifts and inheritances, any size	Settlements, back benefits, wrong outright inheritances	Smaller amounts; no family trustee ready

CONFIRM: **Ask a special-needs lawyer** which trust type fits a given pot of money. The "whose money is it" test from Chapter 4 decides. Getting it wrong hurts benefits.

Chapter 6 — Using ABLE and SNTs Together

Most families do not pick *between* an ABLE account and a special needs trust. They use both. Like a wallet *and* a vault. This chapter is the teamwork manual.

The "Money Lanes" Idea

Think of three separate lanes. Each has its own rules and its own papers:

1. **The SNT lane** — trustee-run, for bigger planned costs. Every payment is weighed against benefit rules.
2. **The ABLE lane** — owned by the person, for flexible daily spending. Deposits stay within the yearly limit.
3. **The payee / DAC lane** — the person's own benefit money (like DAC checks handled by a representative payee). This money belongs to the person. It must be spent on current needs or saved for near needs. It must never mix with anyone else's money. It can go into an ABLE account or a trust only under strict federal rules — see the note below.

The golden rule: **never move money between lanes just because it is easy.** Each move has benefit and tax effects. Move money on purpose, for a reason you can say out loud.

The SNT-to-ABLE Move: The Cleanest Handoff

When the person needs spending money, one of the neatest routes is this: the trustee pays from the SNT straight into the person's ABLE account. Under SSA rules, **SNT-to-ABLE moves do not count as income.** They do not shrink SSI the way cash would. The ABLE account then becomes the person's spending tool. A debit card for food, rides, fun, and other approved costs.

Useful notes:

- The move still counts toward the ABLE **yearly limit** (\$20,000 for 2026). Keep the year's total deposits from all givers under the cap.
- Keep a paper trail: the trustee's note about the move, the ABLE deposit proof, and the benefit check.
- Do not use this route for housing costs without thinking through the housing timing rules from Chapter 3.

ABLE as the Wallet, SNT as the Reservoir

A handy picture:

- **ABLE** = the wallet. Smaller balance. Very flexible. The person (or their helper) spends directly. Great for life's small joys that would be silly to run past a trustee one by one.
- **SNT** = the reservoir. Bigger balance. Trustee-managed. For rent help, big medical bills, equipment, cars, and long-term safety.

Money flows one way — reservoir to wallet — on a set plan. Not in a panic.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Year-by-Year* sheet — watch the balances and the year new SNT money arrives, so you can plan reservoir-to-wallet moves on purpose.

A Note on DAC and Representative-Payee Money

If the person gets DAC through a representative payee (often a parent), that money has its own lane and strict rules. It must be spent on the person's current needs or saved for near needs. It is managed, written down, and reported exactly as the payee rules demand.

Two fine points families miss. First, Social Security *does* let a payee put benefit money into an ABLE account — but only with the right account setup, spending records, and control rules. It is allowed, not a trick — ask the ABLE program how to title it. Second, most payees file a yearly report — but some parents living with the person are excused from the yearly report. Everyone must still keep records and show them when asked.

CONFIRM: **Ask your lawyer** before setting up repeat moves between the SNT and ABLE. And **never** put payee money into a trust without clear legal guidance — that lane has its own federal rulebook. (Payee money must never be added to someone else's trust, like a third-party SNT.)

Sources: SSA POMS SI 01120.201; SSA POMS SI 01130.740; SSA POMS GN 00602.001 (representative payees).

Chapter 7 — Money Planning for a Lifetime

A trust and an ABLE account are tools. This chapter is about the *plan* they serve. The plan must work for decades. Including the decades after the parents are gone. Plan in decades, not years.

Start With the Dream: The Letter of Intent

Before the numbers, write down the life. A **letter of intent** is a paper where parents describe their child. Daily routines. Health history and meds. Favorite foods. How they talk. Friends. Favorite things to do. Faith and culture. Hopes for work or community. What a good day looks like. It tells future trustees and helpers what no legal paper can: *who this person is*.

It cannot be enforced in court. That is its limit and its strength. Because it is informal, you can update it each year as life changes. Write it now. Keep it with the trust papers. Revisit it on birthdays.

Guessing Lifetime Needs

Add up a lifetime of costs in today's dollars. Then adjust:

- **Housing** — the biggest line for most plans. Where will your loved one live at 30? At 60? With family? In supported housing? In a group home?
- **Care and helpers** — paid help hours that Medicaid does not cover.
- **Medical** — premiums, therapies, dental, equipment, and what insurance says no to.
- **Good life** — rides, fun, tech, trips, friends. This is what the trust is *for*. Do not plan a bare-bones life.
- **Rising prices and long life** — costs go up. People with disabilities live longer than ever. Build in cushion.

You do not need a perfect number. You need an honest range. Review it every few years.

PLANNER: Planner companion: Open the *Lifetime Planner* workbook → *Start Here* sheet. Follow the 3 steps in order. Enter your facts in the yellow cells of Parent Inputs. Read your first-gap age in Results. Then study the detail in Year-by-Year.

Funding the Plan

Life insurance is one possible funding tool. Term, whole-life, and universal-life policies have different costs, guarantees, and lapse risks. If insurance is part of the plan, the **beneficiary designation** usually names the third-party SNT rather than the child directly. The right policy and amount depend on the family's budget and health. Compare affordable options, and have the beneficiary designation reviewed before relying on it.

Retirement accounts need extra care. Under the SECURE Act, most inherited IRAs must be emptied within 10 years. But a disabled person can count as an **eligible designated beneficiary** — a special status in the law for a person with a qualifying disability. This can keep payouts spread over the person's lifetime — even through certain well-written trusts, but only with the right trust wording and paperwork. A wrong choice can force a 10-year payout into a trust at high trust tax rates. Get this right with the lawyer *before* you sign beneficiary papers (the forms that say who gets an account when you die). A wrong signature can cost dearly.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Social Security* sheet. Compare Parent 1 claim ages 62–70. Find the age that gives the most lifetime family and DAC money. Do this before you lock in a choice.

Family teamwork: tell grandparents and relatives — in writing, plainly — to name the SNT (not the person) in their wills, insurance, and gifts. One kind outright gift can undo years of planning.

Wills and Papers

- **Wills** should pour money into the SNT. Never straight to the person.
- **Beneficiary papers** (beneficiary designations) on insurance, retirement accounts, and annuities should name the trust. Check every policy and account. These papers beat wills.
- **Power of attorney and health-care papers** should exist for the parents too. If the planners cannot act, the plan stalls. The adult child may also need them, done the right legal way.
- **Guardianship and other options:** at 18, a person is legally grown, disability or not. Choices range from full guardianship (a court picks someone to decide) to **supported decision-making** (the person keeps legal power and picks helpers to explain choices). The right answer fits the person's real abilities. Courts now prefer the lightest option that works.

Benefits as the Foundation

Check every funding choice against Chapter 2's benefits. Life insurance owned the wrong way. A retirement account left outright. A house signed over directly. Each can crack the foundation. The lawyer's job: make the private plan sit *on top of* benefits. Never instead of them.

The Checkup Rhythm

Plans go stale. Review the whole plan:

- **Every 3–5 years** as a habit.
- **Right away** after big life events: a new diagnosis, a move, a marriage or divorce, a death, a big gift.
- **When laws change:** benefit rules, tax rates, and ABLE limits all move. (The 2026 ABLE age change is a perfect case — millions of families should recheck their plans because of it.)

The Team — What Each Player Does

- **Special-needs lawyer** — the architect. Writes trusts, handles guardianship, guards benefits, ties the estate together. Hire for *special-needs* skill, not just wills.
- **CPA or tax pro** — the engineer. Trust tax returns, tax math, estimated payments, tax choices. Pick one who does trust returns (Form 1041) often.
- **Money advisor who knows special-needs families** — the builder. Investing inside the trust, insurance review, funding guesses. Ask how many special-needs families they serve.
- **The trustee** — the keeper. Day-to-day and year-to-year running (Chapter 4).

No one pro covers all four jobs. If someone says they do, get a second view.

CONFIRM: **Ask a special-needs lawyer** before changing any will, beneficiary paper, or insurance owner — and have the CPA review anything with retirement accounts. These are the highest-stakes papers in the plan.

Chapter 8 — Do the Homework Yourself: How Preparation Cuts Fees

Lawyers and CPAs sell time by the hour. Special-needs work is hourly work. A family that walks in with neat facts, a drafted letter of intent, a paper packet, written questions, and a first-try lifetime plan is buying a *review*. A family that walks in with a shoebox is buying a *dig* — and digs cost far more. This chapter is about doing all you safely can yourself. Then the expert's hours go to judgment, not typing.

The Money Math, Plainly

A typical job has three parts: **gather** (collecting your facts), **study** (applying law and math), and **decide and write** (advice and papers). You can do most of the gathering. You should not try the legal study or the writing. The sweet spot: you bring a full, neat package. The expert spends hours only on what only they can do. Families cut the bill a lot this way. Not by haggling. By needing fewer hours.

The Prep Pack: Five Jobs to Finish Before the First Meeting

1. Fill in the Lifetime Planner. Open the *Lifetime Planner* workbook. Work the yellow cells on the *Parent Inputs* sheet: timeline, family basics, Social Security facts, benefits, costs, SNT and gift guesses, ABLE numbers. Then read the *Results* sheet. The first age with a money gap is the most important number in your plan. Study the *Year-by-Year* sheet to age 100. Look hard at the year any gift arrives. Use the *Social Security* sheet to compare claim ages before the meeting. Arrive with a view, not a blank mind.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Start Here* sheet — it walks you through the 3 steps in order and shows your quick-result panel.

2. Write the letter of intent. Chapter 7 told what it is. Now write it. Aim for a few honest pages: routines, health needs, likes, people, hopes. It need not be pretty. It must be true. Bring the draft. The lawyer will say if anything in it fights the trust words.

3. Gather the paper pack. The planner's *Advisor & Sources* sheet has a "Papers to bring" list. It covers the trust papers (if any), SSA benefit letters, ABLE statements, insurance and gift papers, money statements, recent tax returns, and your care budget. Put them in one folder — paper or digital — before the meeting.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Advisor & Sources* sheet — print the "Papers to bring" list and check items off as you collect them.

4. Write down your questions. The same sheet has a "Questions to ask" table. It lists good questions by topic: family top amount, DAC timing, SSI and Medicaid teamwork, trust words, ABLE rules, trust taxes, investing. It says who should answer each one and why it matters. Add your own. A written list keeps a costly meeting on track.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Advisor & Sources* sheet — the "Questions to ask" table shows which expert owns each question.

5. Build the care budget and benefits snapshot. Write the real yearly cost of your loved one's life: housing, care, medical, therapies, good life. List each benefit now received, with amounts. The planner's *Benefits Checklist* walks through life events that change benefits. If your loved one works, the *Wage Log* keeps the pay-report record SSA wants.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Benefits Checklist* sheet — review the 14 life-event rows and mark which ones fit your family this year. PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Wage Log* sheet — log each pay month, gross pay, and how you told SSA. Save the proof.

What NEVER to Do Yourself

Preparing has a hard edge. Do these yourself and you can cause the very harm this booklet fights:

- **Writing the trust.** One wrong word — "must support" instead of "extra help" — can make the whole trust count and kill benefits. Trust writing is lawyer work. Full stop.
- **Tax choices.** The 65-day choice, year choices, grantor-trust wording — these cannot be undone or have hard due dates. Thousands of dollars ride on them. The CPA makes these calls.
- **Benefit calls.** Does a payment count as income? Is a thing savings? Does DAC change Medicaid? These turn on SSA and state rules that shift. Your job: bring the facts. The lawyer's job: apply the rules.

Think of it this way. You can gather your own lab tests. But you do not read your own X-ray. Gathering: you. Reading: them.

How to Hire the Expert — for Review

When you call, say the sentence that sets the job: *"I made a full pack — plans, papers, questions — and I want a review job: check my work, flag problems, tell me what to fix."* Put it in the hire letter:

- **Scope:** review of the family's pack, a written list of problems found, and exact fixes — not planning from zero.
- **Fee:** ask if they will do it for a set price (common for reviews) or by the hour with a cap. Get the cap in writing.
- **What you get:** leave with marked-up papers and a written fix list — not just a chat.

If the expert will not do a review job and insists on starting over, that tells you something. Get a second price.

Running the Investments Yourself: Software Instead of AUM Fees

Legal and tax review is one thing. *Running investments* is another. It is where families quietly lose the most money. Most money advisors charge an **AUM fee**. AUM means "money they handle for you." The fee is a slice of that money each year — often about **1%** (usually 0.5% to 1.5%). It is taken each year, up or down market. On \$500,000 that is \$5,000 a year. On \$1 million it is \$10,000 a year. Each year, for decades. The lost growth is huge: over 20 to 30 years, six figures that could have stayed in the trust go to the advisor instead.

Doing it yourself has two parts. Both can be learned:

- 1. Steady, dull investing.** Put money in regularly. Use broad, cheap index funds. Rebalance to your mix once a year. Learn the basics of *when* selling helps or hurts (mostly a tax question — Chapters 9 and 10 teach it). The facts are on your side: most pros do not beat a simple index mix after fees, over long years.
- 2. Planning software for choices.** Planning tools can do much of what an advisor's costly software does. They cost about \$100 to \$170 a year. Each tool shines at a different job. Pick the one that answers *your* biggest question:
 - **Start with Boldin** (boldin.com — once called New Retirement). Best first pick for most families who want to plan on their own. It walks through your whole money picture. It explains results in plain words. It lets you test choices: retire sooner or later, Roth moves, when to claim Social Security. Free tier too. Full version was about \$144 a year at last check. (Price was set to rise to \$168 for new buyers after October 2026 — check today's price.) Boldin also sells a flat-fee planner check (about \$3,200, no yearly slice).
 - **MaxiFi** (maxifi.com — about \$149 a year) when Social Security and "what can we safely spend?" are your big questions. It handles Social Security for a disabled child head-on.
 - **Pralana** (pralanaretirementcalculator.com — about \$119 the first year, then \$89) for families who love detail and want to check each sum themselves. A family plan lets you build one plan for the parents and one for the child.
 - **ProjectionLab** (projectionlab.com — about \$129 a year) for visual learners. It draws money flows as pictures. Pictures can make long-term trade-offs click.
 - **RightCapital or eMoney, through an advisor**, for families who want a pro to build and tend the plan. Strong tools plus a skilled person — but you pay the advisor too.

One honest warning: **no home tool has been shown to do the whole special-needs job alone** — SSI, DAC, Medicaid, ABLE rules, trust taxes, *and* the child's full life after both parents die, all figured as one. That is why this booklet pairs software with the companion *Lifetime Planner*. The planner was built for that one job: the child's lifetime, year by year.

Match the tool to your question. Just starting to save? Learn what you can spend and save. Near retirement? Weigh taxes and Social Security timing. Scared about after you are gone? You need a plan that runs through your child's whole life — not just yours.

Before you pay for any tool, ask the seller to show you five things: 1. **Separate piles**. Parents' money, the child's money, ABLE, and trust funds must stay in their own piles. 2. **Shifting benefits**. Show the child's income before you retire, after you retire, and after a parent dies. 3. **The child's whole life**. Costs and money must run past both parents' deaths. 4. **True costs**. Housing, paid help, trustee fees, and taxes must be in the sums. 5. **Show the work**. The seller must say which numbers the tool finds and which ones you typed.

Prices move — check before you buy. Treat a tool's tax sums as a start for your CPA, not the last word.

When doing it yourself works: you will keep investing on a schedule. You can leave the money alone when markets fall. Your money picture makes sense to you. That fits most families most of the time.

When paying the yearly fee may truly pay off — judge this with math, not fear: - **Knotty money**. A trust plus a business plus many-state taxes plus a moving estate is truly knotty. A good advisor can earn the fee in tax and setup choices. - **Panic risk**. If you know you will sell in a crash, an advisor who keeps you invested can be worth more than the fee. Be honest about who you are. - **No time or care to learn**. Doing it yourself costs your hours. Price them. - **Trustee duty**. Whoever runs the trust's investments owes a *careful-investor* duty under law. Doing it yourself does not lower that bar. If the trustee is not at ease with that job, a pro helper (or company trustee) may be right. Write the investment plan down either way.

Before you sign: ask just what is covered. Ask if the fee can drop (often yes, above \$1 million). Read the advisor's Form ADV — the SEC paper that lists fees, conflicts, and past trouble. Then do the lifetime math: will the advisor's worth, after the fee, beat doing it yourself? If yes, hire gladly. If no, each fee dollar you skip grows inside the trust for your child's lifetime. That is this whole booklet's mission.

CONFIRM: Ask a trusted money pro before changing how the trust itself is invested. The trust's investment plan should be on purpose and written down. This holds whether you run it or hand it off.

The Three-Way Tug

The planner makes hard trade-offs easy to see. Three needs pull the same dollars:

1. **Parents' old-age money**. First run the numbers with retirement savings whole. If the plan only works by draining the 401(k), the plan is telling you something is off — not a poorer old age. A funding gap calls for comparing affordable options: benefits, support arrangements, spending guesses, and timing. More insurance is one possible answer, but only if the premiums stay affordable year after year. Retirement accounts also have shields a trust cannot copy. And **a trust cannot pay you back** for money you put in early.
2. **The family's way of life**. Brothers' and sisters' school. A steady home. A sound marriage. The year-by-year view lets the family see what each choice costs, in dollars and years. No more fighting from fear.
3. **Therapies needed now**. Therapy and care bills are real and now. Pay them *today* from the ABLE account or today's income. Not by raiding the thirty-year pool.

Model the trade-offs in the planner. Bring the printout to the review. "Here are three plans" is a far cheaper talk than "tell us what to do."

Red Flags: Call Now, Don't Wait

Some events cannot wait for the next checkup. Call the lawyer (and the CPA, if money moved) at once if:

- **A gift or inheritance is about to land in the person's own name** — get benefits counsel *before* it arrives. Do not turn it down, send it elsewhere, or give it away on your own: a mishandled refusal can trigger transfer penalties, and money already belonging to the person cannot simply become third-party trust money. Saying no the wrong way can be worse than saying nothing. This move has hard due dates — call the lawyer first.
- **You get an SSI letter** — too much paid, benefits stopping, or a review. These have short due dates (often 10 to 60 days). Appeal rights run out.
- **A trust money due date is near** — an insurance bill due, a funding window, a giver in poor health.
- **The person's home changes** — a move can reset SSI, Medicaid, and housing help all at once.

CONFIRM: **Ask your lawyer and CPA** to confirm your prep pack is full and right before you act on any of it. Homework saves money. Expert review keeps it safe.

Chapter 9 — How Trust Money Is Taxed

This is the chapter most families never get. It is the one that quietly costs trusts the most money. Tax law treats trusts as taxpayers. And it taxes them *hard* compared to people. Learning why is the key to all of Chapter 10.

Two Tax Types

Each trust has one of two tax types:

- A **grantor trust** is unseen by income tax. All its income is taxed to the maker (or sometimes the person), as if the trust were not there. First-party SNTs are usually this kind.
- A **non-grantor trust** is its own taxpayer. It files its own return (IRS Form 1041). It figures its own tax. It pays its own tax.

One more tax break to ask about: a trust that meets the federal *qualified disability trust* rules can shield about **\$5,300** of income for 2026 — far more than the usual \$100–\$300 trust exemption. Not every SNT qualifies; the papers and the beneficiary must meet the tests. Ask the CPA whether your trust qualifies.

A normal third-party SNT is a non-grantor trust. From here on, "the trust" means that kind, unless we say otherwise.

The Squeezed Tax Steps — The Most Important Fact

People do not hit the top 37% federal tax rate until over \$640,600 of income (single, 2026). A trust hits 37% at just over **\$16,000**. The 2026 federal steps for trusts (IRS Rev. Proc. 2025-32):

Taxable money	Rate
\$0 – \$3,300	10%
\$3,301 – \$11,700	24%
\$11,701 – \$16,000	35%
Over \$16,000	37%

Long-term capital gains and qualified dividends use separate 0%/15%/20% rate bands: 0% to \$3,300, 15% from \$3,301 to \$16,250, and 20% above \$16,250. And trust investment money in the top step also faces an **extra 3.8% investment tax**. So a trust can pay 40.8% federal on plain investment income, or 23.8% on long-term stock gains.

Not all growth is taxed the same: plain interest and short-term gains use the harsh steps in the table; long-term capital gains and qualified dividends get the gentler 0%/15%/20% steps. The CPA sorts each dollar into its bucket — the trustee's job is to know the buckets exist.

These are step rates (only the dollars *in* each step pay that step's rate). But the message is clear: **money left to pile up inside a trust is taxed far harder than the same money in a person's hands**. Congress meant it that way. They want trust money paid out, not hoarded.

DNI: The Tool That Moves Taxable Money Out

DNI stands for Distributable Net Income. It is a tax measuring cup — not a cap on what the trust may pay out. It does two jobs at once:

1. It caps the trust's **tax break for paying out** — the trust deducts the smaller of (a) what it paid out or (b) DNI.
2. It caps how much *taxable income* rides out to the person — the person reports the smaller of (a) what they got or (b) DNI. They get a **K-1** tax form. A K-1 is the paper the trust sends showing the tax items passed to the person — not simply cash received. The person lists it on their own tax return and pays at their own lower rates.

A trust can pay out more than DNI if its papers allow — for example, dipping into the main pile (principal). The extra is not deductible, but the payment itself is not capped by DNI.

In plain words: when the trust pays its income to the person, the tax bill moves too. It leaves the trust's harsh tax steps. It enters the person's gentler ones.

A worked example. Say a trust earns \$30,000 of interest and short-term gains in 2026. It pays \$30,000 to the person for approved costs.

- *If the trust keeps it:* the tax steps bite hard. About \$3,300 taxed at 10%. About \$8,400 at 24%. About \$4,300 at 35%. About \$14,000 at 37%. The federal bill is around **\$9,000+** (before the extra 3.8% investment tax).
- *If the trust pays it out:* the trust deducts the \$30,000 and owes zero on it. The person reports \$30,000 on their K-1. If the person is in the 12% tax step, the tax is about **\$3,600** — and the person's standard tax-free amount may shield part of it fully.

Same money. Very different tax. That is why Chapter 10's first tip is "pay the income out." (Benefits first, always, from Chapters 4 and 6: a payout that saves \$5,000 in tax but costs \$9,000 a year in SSI is a bad deal.)

PLANNER: Planner companion: Open the *Lifetime Planner* workbook → *Year-by-Year* sheet. Check the "estimated SNT income tax" column to see what the trust pays each year when money stays inside.

The 65-Day Rule: The Trustee's Fix-It Tool

Trustees often do not know the trust's exact income until January. That is when the 1099 tax papers arrive — after the year is closed. Congress gave a fix: law § 663(b). Payments made in the **first 65 days** of the new year (by March 6 most years) can count as if made on December 31 of the old year. You make this choice on the trust's tax return.

How it works, step by step:

- **During 2026:** the trustee pays out as needed, minding benefit rules.
- **January into early 2027:** the 1099s arrive. The CPA figures DNI and sees how much money would be stuck in the trust.
- **By March 6, 2027:** the trustee makes a catch-up payment if it is benefit-safe. The CPA marks the § 663(b) choice on the 2026 Form 1041.
- **Result:** the money is taxed to the person for 2026, not to the trust at 37%.

The Stock-Gains Trap

Here is the sneaky one. By default, **stock gains go to the main pile (principal), not to DNI** — so they do *not* flow out with payments. A trust can pay out every dollar of interest and dividends, and still owe 20% plus the extra tax on stock gains stuck inside.

Dodging the trap takes planning. The trust papers can say stock gains count as part of DNI. Or the trustee can be given the power to move gains to income. But state law and the papers' words decide what is allowed. This is a talk to have with the lawyer *when the trust is made or redone*. Fixing it later is hard — it depends on the papers, state law, and what the trustee is allowed to do — so do not count on a last-minute rescue.

State Income Taxes

Some states copy the federal way. Some tax trusts by where the trustee, person, or maker lives. A few have no income tax at all. A trust can touch more than one state. Ask the CPA which state (or states) gets a return.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Parent Inputs* sheet — the SNT part's simple trust-tax guesses feed the whole plan; swap in your CPA's numbers.

CONFIRM: **Ask the trust's CPA** before year-end: how much DNI is still unpaid, whether a 65-day payment makes sense, and how the trust papers treat stock gains. Trust tax planning happens in November and January — not in April.

Sources: tax law §§ 641–663; IRS Form 1041 and Schedule K-1 instructions; IRS Rev. Proc. 2025-32.

Chapter 10 — Paying Less Tax on Trust Money

Chapter 9 told *why* trusts are taxed hard. This chapter is the playbook for lawfully shrinking the bill — seven tips, each with honest warnings. One rule runs this whole chapter. Read it once; use it everywhere:

Tax savings never beat keeping benefits. A tip that saves \$4,000 in income tax but risks \$12,000 a year in SSI and Medicaid is not a tip. It is a mistake. Use each tip below only *after* the benefit check in Chapters 4 and 6.

Tip 1 — Pay DNI Out to the Person

The biggest win, straight from Chapter 9's example: pay the trust's income (up to DNI) so it is taxed on the person's own return, not at the trust's harsh rates. How it works — tax break for the trust, K-1 for the person — is the CPA's job. The trustee's job: make sure each payment is benefit-safe first. Pay sellers. Use the ABLE route where it fits. Watch housing.

Warning: never pay *cash* to the person just for tax reasons. Cash counts as income for SSI. Use sellers or the ABLE account. Write down the benefit check for each payment.

Tip 2 — Use the 65-Day Choice

You need not get the payment amount just right by December 31. Pay your best during the year. Then use January and February to top up: once the 1099s come and the CPA figures DNI, pay any leftover income by early March and mark the § 663(b) choice. This one habit — a "January tax review" with the CPA — wastes less trust tax than any other.

Warning: the choice must go on a tax return filed on time. And the payment must truly happen inside the 65 days. Put it on the calendar. Do not trust memory.

Tip 3 — Put Assets Where They Are Taxed Least

Not each dollar inside the trust must make taxable money each year:

- **Plain index stock funds** make fairly little yearly taxable money. Most growth sits unsold.
- **City and state bond interest** is free from federal income tax. (A twist for the CPA: this interest still touches DNI math, so it is no magic wand — but it cuts the federal bill.)
- **Fast-trading or high-payout funds** inside the trust make plain income taxed up to 37% plus the extra tax — the worst home for them.

The trust's investment plan should weigh both the tax steps *and* the person's long timeline. This is a three-way talk: trustee, money advisor, CPA.

Tip 4 — Time Stock Gains and Losses on Purpose

Since gains often get stuck in the trust (Chapter 9's trap), choose *when* to lock them in:

- **Sell losers to offset winners** in the same year. This is one of the few levers fully in the trustee's hands.
- **Spread big sales** across years when you can. Long-term stock gains get better rates than the 37% top income-tax rate — but trusts still hit their top gain rates at modest dollar amounts, so bunching years of growth into one sale year stays costly.
- **Think about the death step-up:** things the *maker* holds until death often get a higher tax value at death, which can mean less tax on sale. Things inside a lasting non-grantor trust often do not. *Where* high-growth things sit — in the trust, or with the maker with the trust named at death — is an estate choice with income-tax effects. Raise it with the lawyer.

Tip 5 — The Maker-Pays-Tax Choice

Some third-party trusts are written on purpose so the *maker* (often a parent), not the trust, pays the income tax. When the maker pays the trust's tax, it works like an extra **tax-free gift** to the trust. The trust grows untouched while the maker's own return takes the income. It also skips the harsh trust tax steps fully.

Warning: this is a writing choice made when the trust is born. It cannot be glued on later without redoing the papers. It means the maker pays a bigger personal tax bill each year. It usually ends when the maker dies, and the trust becomes its own taxpayer. Model it with the lawyer and CPA before you pick it.

Tip 6 — Gifts to Charity Need CPA Guidance

If the trust papers allow charity gifts, they can do true good — and they follow their own tax rule, not the same one as payments to the person. Do not assume a charity gift carries out DNI the way a person payment does. The papers must *say so plainly* — trustees cannot invent charity power — and the CPA must bless the tax treatment before you give.

Tip 7 — Match Up Estimated Payments (Form 1041-T)

When money is pushed out to the person late, the person may owe tax on income that had no withholding. A 65-day payment is a common case. The trustee can file **Form 1041-T** to allocate part of the trust's estimated tax payments to the beneficiary; it does not allocate withholding. **Watch the deadline:** Form 1041-T is generally due by the 65th day after the tax year ends (March 6 for a calendar-year trust) — a separate deadline from the trust's own return. Ask the CPA about it each year a large K-1 goes out.

What NOT to Do

- **Do not pay out for tax reasons alone** if the payment hurts benefits. Benefit check first, each time.
- **Do not mix** trust money with your own. It wrecks the books the CPA needs. It can put the trustee in legal danger.
- **Do not guess DNI.** It is a figured tax number, not a bank balance. The CPA figures it. The trustee acts on it.
- **Do not skip the return.** A non-grantor trust must usually file Form 1041 each year if it has any taxable income or \$600 or more of gross income — even with no payouts, and even if it owes no tax.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Parent Inputs* sheet — the SNT part's simple trust-tax guesses feed the whole plan; swap in your CPA's numbers. PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Advisor & Sources* sheet — bring the CPA questions to your January tax review.

CONFIRM: **Ask the trust's lawyer and CPA** before using any of these tips. Each one touches the trust's words, the person's benefits, and that year's tax numbers — all three must line up.

Chapter 11 — Keeping Records and Working With Your Team

The dull chapter that saves families in audits, benefit reviews, and trustee handoffs. Good notes prove — to SSA, to Medicaid, to the IRS, and to the next trustee — that each dollar was handled right.

What to Keep, and Why

- **The trust papers and any changes** — the boss of everything.
- **The letter of intent** — updated each year (Chapter 7).
- **Payment notes** — for each one, write: what was asked, the benefit check (why this way of paying), how it was paid (seller, ABLE move, and so on), receipts, and the trustee's okay note. Notes written at the time beat memory later.
- **ABLE statements** — money in, money out, year-end balance.
- **Tax papers** — Forms 1041, K-1s sent out, 1099s received, prepaid-tax proofs, 65-day choice papers.
- **Benefit letters** — SSI award letters, review notices, Medicaid letters, payee reports.
- **Expert hire letters and advice notes** — proof you asked trained people.

PLANNER: **Planner companion:** Open the *Lifetime Planner* workbook → *Benefits Checklist* sheet — file benefit letters with the life-event row they fit, so none go missing before a renewal. PLANNER:

Planner companion: Open the *Lifetime Planner* workbook → *Wage Log* sheet — keep the SSI pay-report log with your benefit papers. It is the proof SSA asks for at reviews. PLANNER: **Planner**

companion: Open the *Lifetime Planner* workbook → *Advisor & Sources* sheet — use the "Papers to bring" list as the master list of what this file should hold.

Keep everything at least seven years. Keep the trust papers and letters of intent forever.

The Yearly Checklist

Run through this each year. January is best, right when the 1099s arrive:

- ☐ Last year's Form 1041 filed; K-1s sent to the person
- ☐ 65-day window checked with the CPA — any catch-up payment needed by early March?
- ☐ ABLE room checked for the new year (\$20,000 limit for 2026 — check the current year's number)
- ☐ Prepaid taxes set right for the coming year
- ☐ Benefit review papers ready (income and savings proof on hand)
- ☐ Money review with the advisor — are assets still in tax-smart spots?
- ☐ Letter of intent updated
- ☐ Lawyer check-in: any law changes touch the plan? Any papers need updates?
- ☐ Backup trustees still current (people move, age, grow unable)

When to Call Whom

Problem	Call
Odd or large payment; changing the trust; law changes; guardianship questions	Special-needs lawyer
DNI math; prepaid taxes; 65-day choice; K-1 questions; 1041-T	CPA / tax pro
Where money is invested; insurance review; funding guesses	Money advisor (special-needs skilled)
Benefit questions; reporting a change; review help	SSA / state Medicaid office
Day-to-day spending inside the trust's normal pattern	The trustee (that is the job)

If Something Goes Wrong

Too much paid. A missed filing. A payment that hurt benefits. These happen. The fix pattern: **stop, write it down, tell, and get expert help before the next due date.** Fixing it yourself is almost always cheaper than being caught. Keep who-to-call simple: lawyer for legal and benefit trouble, CPA for tax trouble. Tell both everything. They cannot guard what they do not know.

CONFIRM: **Ask your lawyer and CPA** whether your notes meet your state's rules — some states demand trustee reports beyond what is in this chapter.

Appendix A — Word List

ABLE account — A savings account for people whose disability began before age 46. Growth is tax-free. Money taken for approved disability costs is tax-free. The first \$100,000 does not count for SSI savings limits.

Beneficiary — The person the money is for.

Principal — Trust property accounted to principal, often including contributions and capital gains. It is not the same as income, earnings, or cash.

Income, earnings, and capital gains — Income is a legal and tax category; earnings are amounts an asset produces; a capital gain arises when property is sold for more than its tax basis. These terms are not interchangeable.

Countable savings — Money or things SSI or Medicaid counts toward savings limits (like the \$2,000 SSI limit for one person).

DAC (Disabled Adult Child) benefits — Social Security money paid to a grown-up disabled before age 22. Based on a parent's work record. Also called Childhood Disability Benefits.

DNI — Short for Distributable Net Income. It generally limits the trust's income-distribution deduction and the taxable income carried out to beneficiaries. It does not cap total distributions.

Payment (distribution) — Money or things paid from a trust or account, to the person or for the person.

First-party SNT — A special needs trust funded with the person's *own* money. Must be made before age 65. The state must be paid back at death.

Grantor — The person who makes a trust and puts money in it.

Grantor trust — A trust whose money is taxed to the maker, not to the trust.

Help with housing (ISM) — Housing costs someone else pays for a person on SSI, like rent paid straight to the landlord. It can shrink the SSI check. Since late 2024, food is no longer part of this rule.

K-1 — A tax form that reports tax items passed from a trust to a beneficiary. It does not simply report the cash the beneficiary received.

Letter of intent — A paper from parents to future helpers and trustees. Not a legal paper. It tells the person's needs, routines, likes, and hopes.

Medicaid payback — The federal rule that a first-party trust must pay the state back for Medicaid, from leftover money at the person's death.

Non-grantor trust — A trust that is its own taxpayer. It files Form 1041 and pays tax on money it does not pay out.

Pooled special needs trust — A trust run by a nonprofit group. Many people each have their own part.

Approved disability costs — Costs the ABLE law says are okay, so ABLE money taken for them is tax-free. Housing, school, rides, health, tech aids, job help, and more.

Representative payee — A person Social Security picks to handle benefit money for someone who cannot do it alone. Strict federal rules apply.

65-day rule — A tax rule. Payments made in the first 65 days of a year can be counted as if made on the last day of the year before.

SSI (Supplemental Security Income) — Monthly federal money for people who are aged, blind, or disabled and have low income and savings.

Third-party SNT — A special needs trust funded with *someone else's* money, like family or insurance. No payback to the state. Can be made at any age.

Trustee — The person or company legally in charge of a trust. They manage the money and make payments per the trust papers.

Appendix B — Sources and where to verify

Dollar figures and thresholds change annually. Verify every number that matters to a decision against the current-year source before acting.

- [**IRS Publication 907**](#) — Tax Highlights for Persons with Disabilities (ABLE rules, in plain language).
- [**26 U.S.C. § 529A**](#) — The ABLE statute.
- [**IRS 2026 inflation-adjustment release**](#) — Revenue Procedure 2025-32: 2026 inflation adjustments: \$20,000 aggregate limitation on ABLE contributions (§3.34) and \$19,000 annual gift-tax exclusion (§3.42(1)) — the two diverged starting 2026 under OBBBA §70115; 2026 trust/estate income-tax brackets.
- [**SSA POMS SI 01120.200**](#) — Third-party trusts and trust basics.
- [**SSA POMS SI 01120.201**](#) — How Social Security treats trusts.
- [**SSA POMS SI 01130.740**](#) — How Social Security treats ABLE accounts.
- [**SSA payee and ABLE accounts**](#) — When a representative payee may use an ABLE account.
- [**SSA POMS GN 00602.001**](#) — Representative-payee duties.
- [**IRC § 663**](#) — Distribution rules within the trust-income-tax provisions (IRC §§ 641–663).
- [**IRS Form 1041 and Schedule K-1 instructions**](#) — Fiduciary income-tax return mechanics, including the § 663(b) 65-day election. See also [Form 1041-T](#).
- [**NC Medicaid manual MA-2110, § III**](#) — Worked example of state administration (DAC Medicaid pass-along); readers in other states should consult their own state's Medicaid manual.
- [**SSA POMS SI 01120.203**](#) — First-party and pooled-trust exceptions, including Medicaid payback and age-related transfer issues.
- **The reader's own trust document and ABLE program disclosure booklet** — these control over any general guide.
- **Planning software mentioned in Chapter 8** (prices change — check before buying): [Boldin](#); [MaxiFi](#); [Pralana Online](#); [ProjectionLab](#); [RightCapital](#); [eMoney Pro](#).

Appendix C — How This Booklet Fits With the Trustee Tools

This booklet does not stand alone. It has two working partners:

- **The payment-choice checklist** — walks a trustee through single spending choices step by step: which money lane, what benefit check, how to pay, what to write down.
- **The monthly tracking sheet** — the partner log for money moves, ABLE activity and housing-time alerts, balancing the books, and paper follow-up.

Think of it this way. The checklist and tracking sheet are the *daily tools* — what to do, day by day. This booklet is the *guidebook* — why the tools work the way they do, plus the tax and lifetime-planning material the tools do not cover. Families and future trustees will grab the checklist weekly. They will open this booklet when they need to learn the reason behind a rule — or to explain it to a lawyer, a CPA, or a new trustee.

Appendix D — The Lifetime Planner Workbook: Sheet by Sheet

The *Special Needs Lifetime Planner* is the workbook that turns this booklet's ideas into your family's numbers. It is a planning tool only. Its own warning says to check Social Security numbers, taxes, legal issues, and benefit rules with experts. Any starting examples in it are not your facts. Replace them with your own numbers.

Sheet	What it does	Goes with
Start Here	The front door: 3 steps (enter facts in Parent Inputs → read Results → study Year-by-Year), a quick-result box (first gap age, Parent 1 claim age, SNT funding year), and the planner's warning	Chapters 7, 8
Parent Inputs	The yellow cells you fill in: timeline, family basics, Social Security facts, benefits, costs, SNT and gift guesses, ABLE numbers	Chapters 3, 4, 7, 8, 9, 10
Results	The answer page: first age with a money gap, money left at the end age, Parent 1 claim-age study, DAC amounts, and how to read it all	Chapters 7, 8
Social Security	Claim-age compare table (ages 62–70) for Parent 1: monthly check, family top amount, DAC after the top, and the "best" age	Chapters 7, 8
Year-by-Year	The full plan to age 100: benefits, costs, ABLE and SNT balances and growth, new SNT money, trust tax money, planned SNT income tax, trustee fees, money gap	Chapters 6, 7, 8, 9
Advisor & Sources	"Questions to ask" table (topic, question, who checks it, why it matters, source links) plus the "Papers to bring" list	Chapters 4, 8, 10, 11
Benefits Checklist	14 life-event rows (DAC sign-up, Medicaid renewals, SSI reviews, ABLE deposits, housing money out, SNT changes...) with what to do for each	Chapters 2, 3, 8, 11
Wage Log	SSI pay-report log: pay month, gross pay, told-SSA status, how, proof saved, notes	Chapters 2, 8, 11

Work the sheets in the order *Start Here* gives. Bring the filled workbook to each expert meeting — it is the heart of the prep pack in Chapter 8.

Appendix E — Share This Free Toolkit

This booklet and the companion *Lifetime Planner* workbook are free to share. You may copy them and give them to any family, group, or helper who needs them. You may not sell them, and you may not use them to sell something else. That is the whole rule. (Formally: shared under a Creative Commons Attribution-NonCommercial 4.0 International license — CC BY-NC 4.0.)

If this toolkit helped your family, the best thank-you is to pass it to another family who needs it.