

Special Needs Family Financial Planning

A Free Practitioner Reference

From The Baratelli Institute.

Free for families and practitioners worldwide.

Mentoring at scale.

INSIDE

- Special Needs Trusts, ABLE accounts, Letter of Intent
- Preserving SSI, SSDI, and Medicaid while building wealth
- Insurance strategy for parents funding the trust
- A life-stage map: birth through parental death planning
- 50-state + DC resource appendix and a 2026 quick-reference table

From The Baratelli Institute

An author's note. My daughter taught me about families who arrive at hospitals far from home with a child receiving serious medical care. She introduced me to the work of hospitality houses — places where parents walk into a real bedroom and a real kitchen rather than a hotel room, where someone hands them coffee at three in the morning, where other parents understand. The compound-interest tool I had built for the Institute became, in that moment, a different kind of question: the same patient, practical math we use for business owners and investors is exactly what these families need, only with higher stakes and less time to learn it. This reference is the form that thank-you took. It is honest, practical, and deliberately uncluttered. The Institute publishes it free of charge, with no advertising, no upsell, and no requirement to register. We hope it earns a spot in your kitchen drawer.

— *The Baratelli Institute*

A note on international applicability

The mechanisms described in this reference — separating asset ownership from beneficiary access, coordinating government benefits with private resources, sequencing decisions across a child's lifecycle, and structuring estate transfer to preserve both eligibility and dignity — are concepts that translate broadly across legal jurisdictions. The specific statutory references (the U.S. §1917(d)(4)(A) and (d)(4)(C) trust authorities, U.S. Social Security Disability Insurance, U.S. Medicaid, U.S. §529A ABLE accounts) are American. International readers should expect the framework to be useful and the specifics to require translation: most developed jurisdictions have analogous trust structures, disability-benefit programs, and means-tested support frameworks under different names. Please consult counsel licensed in your jurisdiction for the local-statute version of every mechanism cited.

TRANSLATION NOTE

What carries across borders, and what does not

Carries across: the architecture (trust separating ownership from access; documented narrative care instructions; staged funding during parents' lives plus a death-funded second tier; benefit-aware vendor-direct distributions; sequencing tasks across the child's lifecycle). **Requires local translation:** the names of statutes and agencies, the precise asset and income thresholds, the tax treatment of trusts, the rules on payback and remainder beneficiaries, and the availability of “ABLE-equivalent” savings vehicles. Counsel in your jurisdiction is not optional — it is the only way to ensure the framework lands correctly in your legal system.

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How to use this reference

The kindest thing a parent can do for a special-needs adult child is to leave a clean, current, well-briefed architecture behind. This reference is the map for building it.

It is a reference book — not a workbook you fill out in order. It is designed for a parent or grandparent who has fifteen minutes after the house is asleep — not for a long evening at a desk.

Read Part I once, end-to-end. It is the foundation, and the rest will make more sense if you have it. After that, use the table of contents and the decision tree in Part V to jump to what you need. The two state appendices at the back are designed to be consulted by readers in any of the fifty states or the District of Columbia.

WHY THIS MATTERS

The single most actionable first step

If this reference feels like too much to read right now — and at the point of diagnosis, that's the most common feeling — the most useful single step you can take is contact your state's PTI (**Parent Training & Information Center**). Every state has one, federally funded under IDEA. They provide free training, advocacy support, IEP navigation, and transition planning. One member of our editorial committee — a parent of an adult child with disability — said she refers families to her state PTI office multiple times every day.

See Appendix C on page 82 for your state's PTI office. It's a 51-row chart. Find your state, call the number, leave a message describing your situation. They will call you back. If the guide accomplishes nothing else, getting you to that call is a success.

STATE/LOCAL RESOURCE

Resources in the back of this reference

This reference ends with six state-by-state and federal resource directories — public-agency-only, no private referrals. If you're searching for a specific resource, you can jump to the back at any time:

- Appendix A — Health, Disability & Advocacy Agencies (50 states + DC) ... p. 68
- Appendix B — Education, Employment & Coordination Agencies (50 states + DC) ... p. 74
- Appendix C — Parent Training & Information Centers (PTI / CPRC) by state ... p. 82
- Appendix D — Assistive Technology Act State Programs ... p. 85
- Appendix E — Federal Statutory & Landmark Case Index ... p. 90
- Appendix F — Title V Children & Youth with Special Health Care Needs (CYSHCN) ... p. 95

You don't need to read the reference in order to use these. They are reference charts. Flip back as needed.

Callout boxes you'll see throughout:

Three callout types appear throughout this reference. Each is distinguishable by border treatment as well as color, so the structure survives a black-and-white printout. The leading label — **WHY THIS MATTERS**, **WORKED EXAMPLE**, **STATE/LOCAL RESOURCE** — also tags each box so the type is identifiable without reference to color.

WHY THIS MATTERS

The principle behind the page (navy box; double rule top and bottom)

WHY THIS MATTERS boxes explain why a rule exists. They are short. They are the part you should remember six months from now even if you forget the details on the rest of the page. In color, they are navy; in black and white, look for the heavy double rule running top and bottom of the box.

WORKED EXAMPLE

A concrete number, run through the math (cream box; single thin border)

WORKED EXAMPLE boxes show a real calculation — family setup, dollar amounts, the answer. Names are illustrative. The math is real and the assumptions are stated, so you can re-run it with your own numbers. In color, the fill is cream; in black and white, the box carries a single thin border with no rule emphasis.

STATE/LOCAL RESOURCE**A jurisdiction-specific pointer (gold box; thick left bar)**

STATE/LOCAL RESOURCE boxes flag a state agency, regional resource, or state-specific rule. The principle applies in every state; the agency name, waitlist, and intake details differ. Use Appendix A and Appendix B at the back to find the equivalent in your state. International readers: see the translation note on page 3. In color, these are gold; in black and white, look for the thick vertical bar running down the left edge.

Throughout, every dollar figure carries a source citation in small type. The complete source list is in the back matter.

Legal note

This reference is published as a free educational resource by The Baratelli Institute. It is not legal advice, tax advice, financial advice, or investment advice. Special-needs planning is intensely fact-specific. What is correct for one family is harmful for another — because of the child's diagnosis, the parents' assets, the state of residency, family composition, or a dozen other variables a book cannot see.

Before acting on anything in this book, retain counsel licensed in your jurisdiction with documented special-needs trust experience, and a tax practitioner familiar with disability planning. Counsel drafts the trust documents and reviews benefit interactions. The tax practitioner models the consequences and coordinates ABLE contributions (or the local equivalent). The cost of those two engagements is the cheapest insurance available against the most common, most preventable, and most permanent mistakes in this area of law. This reference does not recommend specific lawyers, accountants, financial planners, or firms; the back-matter section on professional advisors describes the kind of practitioner to look for and where to research credentials, but the selection is the reader's to make.

Numbers in this book are 2026 figures from U.S. federal agencies (Social Security Administration, Internal Revenue Service, Centers for Medicare & Medicaid Services). Limits and thresholds change — verify the current year's figure on the agency website before relying on it. State-specific rules are flagged where they appear; principles apply nationally, but the names, waitlists, and agency contacts will differ. Consult Appendix A and Appendix B for the relevant state-by-state directory. International readers should treat the framework as translatable and the statutory citations as American.

Standing recommendation — build a three-person team early

Most special-needs families end up working with three professionals in an ongoing way. Build the team early — before crisis, before the next diagnosis update, before the inheritance arrives — and the rest of the planning lands much faster. This reference does not recommend specific individuals or firms; the table below describes the role, the qualifications to look for, when to engage, and the questions to ask at the first meeting.

Professional	What they do	When to engage	What to ask
Special-needs counsel	Drafts and updates the Special Needs Trust; advises on SSI / SSDI / Medicaid interactions; counsels on guardianship vs. supported decision-making; coordinates with the tax practitioner and financial planner.	As soon as the diagnosis is documented, or before any inheritance / gift event involving the beneficiary. Re-engage every 3–5 years and after any major life event.	How many d4A and d4C trusts have you drafted in the last twelve months? Are you licensed in good standing in this state? Will you coordinate directly with our CPA and planner?

Professional	What they do	When to engage	What to ask
Tax practitioner (CPA or EA)	Files Form 1041 for the trust; coordinates ABLE contributions; claims the medical-expense deduction (§213), Saver's Credit (§25B), and dependent-care credit (§21); coordinates with counsel on grantor / non-grantor trust elections.	Once the trust is funded or ABLE is opened. Annually thereafter at filing season; mid-year if a major transaction is contemplated.	Have you filed Form 1041 for an SNT in the last twelve months? Are you comfortable with §1917(d)(4)(A) trust accounting? Do you handle ABLE contribution coordination?
Financial planner (fiduciary)	Models the second-to-die life insurance funding scenario; coordinates trust assets with ABLE balances; advises on retirement-account beneficiary designations naming the SNT; runs the long-horizon cash-flow projection.	Once the trust exists and parents have surplus cash flow to fund it. Re-engage annually for the funding model; ad-hoc for major liquidity events.	Are you a fiduciary in writing for the entire engagement? Have you modeled SNT funding scenarios before? What is your full compensation structure, in writing?

National professional associations such as the Special Needs Alliance and the National Academy of Elder Law Attorneys (for the legal role), state CPA societies and the AICPA Personal Financial Planning Division (for the tax role), and the CFP Board, SEC adviser disclosure database, and FINRA BrokerCheck (for the planner role) maintain searchable directories and credential look-ups. None of these is an endorsement; interview multiple practitioners and confirm references before retaining.

A note on language and assumptions

Throughout this reference we use person-first language by default — “your child,” “the young adult,” “the person with a disability” — and reach for the legal term “beneficiary” only where the trust-document context demands it (because that is the word the trust itself uses, and a trustee reading a distribution clause needs to recognize it). Many families and self-advocates prefer identity-first language at home (“my autistic son,” “my disabled daughter”). Both are correct; both are used in good faith by people who love the same person. Substitute the language your family uses as you read.

We assume a family resident in the United States. The legal architecture is federal and translates anywhere in the United States; the Medicaid waiver names, waitlists, ABLE plan names, and agency contacts are state-specific and appear in the appendices at the back. We assume two parents by default in worked examples; single-parent, grandparent-headed, blended-family, and same-sex-parent households apply the same architecture with adjustments counsel in your jurisdiction can flag. We assume the diagnosis is documented and the family is past the first six months of absorbing it — if you are still in that window, the Letter of Intent section in Part I is the gentlest entry point; the rest will keep.

International readers: read “state” as “your jurisdiction” and the U.S. statutory citations as illustrative of structures that exist under different names in most developed legal systems.

Acronyms at a glance — quick reference

This reference uses a number of specialized acronyms common to the disability-services and benefits space. The reference table on the following pages lists every acronym used. Skim it now or flip back as needed. Where a term is defined by federal statute, the governing statute or agency is named. Use together with the Glossary (Part V) for narrative definitions and with the Index at the back for page-level cross-references.

Acronym	Full term	Acronym	Full term
AAA	Area Agency on Aging (Older Americans Act planning & service area)	ILIT	Irrevocable Life Insurance Trust
ABLE	Achieving a Better Life Experience Act (IRC §529A savings account)	IRC	Internal Revenue Code (26 U.S.C.)
ACA	Affordable Care Act (federal health-insurance marketplace law)	LTC	Long-Term Care (insurance and Medicaid services category)
ACL	Administration for Community Living (HHS operating division)	LTCO	Long-Term Care Ombudsman (Older Americans Act §712)
ADA	Americans with Disabilities Act (42 U.S.C. §§12101 et seq.)	LTSS	Long-Term Services and Supports
AT Act	Assistive Technology Act of 2004 (29 U.S.C. §§3001 et seq.)	MCHB	Maternal and Child Health Bureau (HRSA; Title V grantor)
AUCD	Association of University Centers on Disabilities	MEC	Modified Endowment Contract (life-insurance tax classification)
CAP	Client Assistance Program (Rehabilitation Act §112)	MMMNA	Minimum Monthly Maintenance Needs Allowance (spousal-impoverishment)
CELA	Certified Elder Law Attorney (NAELA-administered credential)	MWPD	Medicaid for Working People with Disabilities (Buy-In)
CFP	Certified Financial Planner (CFP Board credential)	NACDD	National Association of Councils on Developmental Disabilities
CMS	Centers for Medicare & Medicaid Services	NAELA	National Academy of Elder Law Attorneys
COBRA	Consolidated Omnibus Budget Reconciliation Act (health continuation)	NDRN	National Disability Rights Network (P&A umbrella)
CPRC	Community Parent Resource Center (IDEA Part D)	NEMT	Non-Emergency Medical Transportation (Medicaid benefit)
CSRA	Community Spouse Resource Allowance (Medicaid spousal-impoverishment)	NPI	National Provider Identifier (HIPAA standard identifier)
CYSHCN	Children & Youth with Special Health Care Needs (Title V program)	OAA	Older Americans Act (42 U.S.C. §§3001 et seq.)
DAC	Disabled Adult Child (SSDI category, Title II)	OBBA	One Big Beautiful Bill Act of 2025

Acronym	Full term	Acronym	Full term
DD	Developmental Disability (DD Act, 42 U.S.C. §15002)	OPWDD	Office for People With Developmental Disabilities (New York state agency)
DDA	Developmental Disabilities Assistance and Bill of Rights Act	P&A	Protection & Advocacy system (DDA-mandated, NDRN-affiliated)
DOL	U.S. Department of Labor	PASS	Plan to Achieve Self-Support (SSI work incentive)
EA	Enrolled Agent (IRS-licensed tax practitioner)	PFS	Personal Financial Specialist (AICPA credential)
EI	Early Intervention (IDEA Part C, birth to age 3)	POA	Power of Attorney
EPSDT	Early and Periodic Screening, Diagnostic and Treatment (Medicaid child benefit)	POMS	SSA Program Operations Manual System
ERISA	Employee Retirement Income Security Act	PTI	Parent Training and Information Center (IDEA Part D)
FBR	Federal Benefit Rate (SSI monthly federal amount)	§504	Section 504 of the Rehabilitation Act (29 U.S.C. §794)
FERPA	Family Educational Rights and Privacy Act (20 U.S.C. §1232g)	SGA	Substantial Gainful Activity (SSDI work threshold)
FPL	Federal Poverty Level (HHS Poverty Guidelines)	SHIP	State Health Insurance Assistance Program (Medicare counseling)
FRA	Full Retirement Age (Social Security)	SNT	Special Needs Trust (first-party d4A, third-party, or pooled d4C)
GST	Generation-Skipping Transfer (federal transfer tax, IRC §2601)	SSA	Social Security Administration
HCBS	Home- and Community-Based Services (Medicaid §1915(c) waiver)	SSDI	Social Security Disability Insurance (Title II)
HIPAA	Health Insurance Portability and Accountability Act	SSI	Supplemental Security Income (Title XVI)
HRSA	Health Resources and Services Administration (HHS)	TBI	Traumatic Brain Injury
IDEA	Individuals with Disabilities Education Act (20 U.S.C. §§1400 et seq.)	UCEDD	University Center for Excellence in Developmental Disabilities
IEP	Individualized Education Program (IDEA Part B)	UTC	Uniform Trust Code
IFSP	Individualized Family Service Plan (IDEA Part C)	VR	Vocational Rehabilitation (Rehabilitation Act Title I)
IHSS	In-Home Supportive Services (California Medicaid personal-care program)	WIPA	Work Incentives Planning and Assistance (SSA-funded counseling)

Source: Acronyms compiled from the federal statutes, regulations, and agency publications cited in this reference. Where an acronym is agency-specific, the governing agency or statute is named in parentheses.

A 30-day starter checklist

~3 min read

For families in the first weeks after a diagnosis. The rest of this reference is the long architecture; this page is the first month. Do what you can. Skip what does not yet apply. Nothing on this list has to be done in a single sitting.

The first weeks after a diagnosis are the worst time to read a 200-item planning manual. This is the short version. It groups the thirty most-useful early steps into four weekly blocks, each designed to fit a single evening at the kitchen table. Cross off what you have done; leave the rest. The architecture in Part I will still be there in a month.

Days 1–7 — gather and document

- Request a written copy of the diagnosis and any supporting clinical reports; ask for them in PDF and on paper.
- Start a single physical binder (or a cloud folder) for medical, school, benefits, and legal documents. Everything in one place from day one.
- If the child is school-age: request an Individualized Education Program (IEP) evaluation in writing. The clock starts when the school receives the written request.
- If the child is under 3: contact your state's Early Intervention (IDEA Part C) program. The state agency name is in Appendix B.
- List the people you trust most — spouse, sibling, close friend, faith community. You will lean on them. Tell them.

Days 8–14 — initial benefits intake

- Run an SSI eligibility screen. The Social Security Administration's online benefit screener (ssa.gov) covers the basic test.
- If the family qualifies, begin a Medicaid enrollment application. State Medicaid agency contacts are in Appendix A.
- File the application for your state's HCBS waiver waitlist the same week. Placement is set by submission date — every week matters.
- Check whether your state has a Children's Health Insurance Program (CHIP) gap that applies while the Medicaid application is pending.

Days 15–21 — begin the legal architecture

- Schedule a first consultation with counsel licensed in your jurisdiction with documented special-needs trust experience. The Special Needs Alliance and NAELA maintain searchable member directories.
- Brief grandparents and other gift-givers: *do not* name the child directly as beneficiary on any account, will, or life-insurance form until the third-party SNT is in place.

- Draft a preliminary Letter of Intent — even one page is enough to start. Section headings are in Part I.
- Pull credit reports for both parents. Special-needs planning often surfaces years of deferred financial cleanup.

Days 22–30 — build the team and the family conversation

- Hold a family meeting — in person if possible, video if not. Brief siblings, grandparents, and any adult who may be asked to step in over the years.
- If appropriate (disability onset before age 46 under the 2026 ABLE Age Adjustment Act), open an ABLE account. Start with a small contribution; the point is to establish the account.
- Add a tax practitioner (CPA or EA) to the team. The Standing Recommendation on page 6 lists the questions to ask at first meeting.
- Add a fiduciary financial planner once the trust framework is in motion. The funding math (Part III) is a planner conversation, not a do-it-yourself one.
- Pencil in a 90-day review meeting with yourself or your spouse. Cross off what is done. Move what is not done into the next month.

WHY THIS MATTERS

Thirty days is enough to lay the foundation

Families often report that the hardest part of special-needs planning is starting. The architecture in this reference is built over years; the first thirty days are about laying the foundation stones — a documented diagnosis, an application on the waiver waitlist, a first conversation with counsel, an ABLE account opened. None of these is irreversible. All of them are cheaper and easier to do in the first month than to retrofit later.

PART I

Financial Architecture of the Special-Needs Family

Three documents and one bank account hold up almost everything else: a Special Needs Trust, an ABLE account, a Letter of Intent, and a trustee who knows what they are doing. Part I explains what each one is, when you use it, and how they fit together over a lifetime.

Special Needs Trust variants — when each one fits

~6 min read

A Special Needs Trust (“SNT”) is a legal container that holds assets for the benefit of a person with a disability without those assets counting against means-tested public benefits such as Supplemental Security Income (SSI) and Medicaid. There are three principal variants under U.S. federal law, and the choice among them depends on whose money funds the trust and where the assets came from.

First-party SNT (d4A trust)

A first-party trust, named for Section 1917(d)(4)(A) of the Social Security Act (codified at 42 U.S.C. §1396p(d)(4)(A)), holds *the beneficiary's own money*. Most often this is a personal-injury settlement, an inheritance the child received directly, or back-Social-Security awards. The beneficiary must be under 65 at the time the trust is established, and on the beneficiary's death, any remaining trust assets must reimburse the state Medicaid program for lifetime benefits paid — the so-called “Medicaid payback” provision. After payback, anything left passes to remainder beneficiaries.

Third-party SNT

A third-party trust holds *someone else's* money for the beneficiary's benefit — typically parents, grandparents, or other relatives. Because the assets never belonged to the beneficiary, there is **no Medicaid payback at death**. Whatever remains passes to whomever the grantor named: siblings, charity, a continuing trust for grandchildren. This is the workhorse vehicle for parental and grandparental gifting and for life insurance proceeds intended for the child's lifetime care.

Pooled SNT (d4C trust)

A pooled trust, named for Section 1917(d)(4)(C), is administered by a nonprofit organization that pools the assets of many disabled beneficiaries for investment purposes while maintaining sub-accounts for each. Pooled trusts are often the right answer when the trust corpus is modest (under \$100,000–\$250,000 is a common rule of thumb), when no suitable individual trustee is available, or when the beneficiary is over 65 (which precludes a new d4A but not a d4C). On the beneficiary's death, the nonprofit's retention practice varies by master document — some retain a portion of the remaining sub-account, others return more to family or to remainder beneficiaries; ask for the specific master trust language before selecting a pool. Medicaid payback applies to any amount not retained by the nonprofit. Pooled-trust availability varies by state and changes over time;

readers should ask the state Protection & Advocacy system or state DD Council (Appendix A) for current options serving their jurisdiction and review each program's master trust language before selecting.

WHY THIS MATTERS

First-party vs third-party is the single most important distinction

Mixing the two is the most common and most expensive mistake in this area of law. If a grandparent's intended gift to the grandchild ends up titled in the child's name first — even briefly — it becomes the child's money and can only go into a first-party trust, which means the state recovers from it at death. Routing the gift directly into a third-party trust preserves the family's ability to name the remainder beneficiaries.

Trust-protector clauses — keeping the trust adaptable

An SNT that is drafted in 2026 will be administered, in many families, into the 2070s or 2080s. The law will change. The Medicaid rules will change. The trustee will likely change more than once. A *trust protector* is a third role — distinct from the grantor and the trustee — given specific powers in the trust document to keep the trust adaptable over decades without going to court. The protector typically can: remove and replace the trustee, modify administrative provisions of the trust to respond to changes in law (notably Medicaid and tax law), resolve ambiguities, and direct the trustee on extraordinary matters that the drafting parents could not foresee. The protector role does not direct routine distributions; that remains the trustee's discretion.

Sample clause language follows. **This is illustrative only — actual trust drafting must come from counsel licensed in your jurisdiction with documented special-needs trust experience, and clause language must be coordinated with the rest of the trust document.**

“The Grantor hereby appoints [Name] to serve as Trust Protector. The Trust Protector shall have, in a fiduciary capacity, the following powers, exercisable in writing: (a) to remove any Trustee, with or without cause, and to appoint a successor Trustee consistent with the qualifications stated in this trust; (b) to modify any administrative or technical provision of this trust to respond to changes in federal or state law affecting the beneficiary's eligibility for needs-based public benefits, including without limitation Supplemental Security Income, Medicaid, and any successor programs; (c) to resolve ambiguities in this trust and to direct the Trustee on extraordinary matters not contemplated by the Grantor; (d) to appoint a successor Trust Protector. The Trust Protector shall not have the power to direct routine distributions, to alter the dispositive terms of this trust, or to benefit themselves. The Trust Protector shall be entitled to reasonable compensation and shall not be liable for good-faith exercise of these powers.”

Choose a protector who is younger than the grantors, professionally competent (often an attorney or CPA outside the trustee firm), and geographically or institutionally independent of the trustee so the removal-and-replace power is meaningful.

Decanting — moving an old trust into an updated one

Even with a trust protector, some older SNTs were drafted with rigid language that no longer fits the beneficiary's needs or the current benefits landscape. *Decanting* is the legal mechanism for “pouring” the assets of an existing irrevocable trust into a new trust with updated terms — typically without court involvement, without tax-event triggers if done correctly, and without disturbing the beneficiary's public benefits. Decanting authority comes from a combination of the Uniform Trust Code (§ 418, where adopted) and individual state decanting statutes; most U.S. states have enacted some form of decanting statute since the late 1990s, though the scope of permissible changes varies considerably state to state. The trustee, not the beneficiary, typically initiates decanting; some states require notice to beneficiaries and to the state Medicaid agency.

Decanting is the right tool when, for example, the original SNT was drafted before ABLE existed and lacks coordination language; when the trustee provisions name people now deceased or no longer suitable; or when changes in Medicaid policy have made certain distribution standards counterproductive. It is not a substitute for a well-drafted original document, but it is a quiet, underused tool for families with older trusts that are otherwise stuck. Counsel licensed in the trust's situs state with trust-decanting experience should run this analysis.

Source: Uniform Trust Code § 418; state decanting statutes — scope varies; ACTEC and Special Needs Alliance position papers on decanting irrevocable trusts.

ABLE vs. SNT — a decision matrix

Most families end up using both an SNT and an ABLE account because each does what the other does poorly. The matrix below is a decision aid for sequencing — when to use one alone, when to use both, and what the determining inputs are. True flowcharts render poorly in print; this is the same decision-tree logic in tabular form.

Decision input	ABLE alone	SNT alone	Both
Beneficiary disability onset	Before age 46 (post-2026 ABLE Age Act)	Any age	Onset before 46 and SNT-funded family
Annual funding capacity	Up to \$19,000 (2026) + ABLE-to-Work supplemental	Above \$19,000/year of family gifting	Family fills ABLE first, then funds SNT for the surplus
Total asset size projected at parental death	Under ~\$100,000 lifetime corpus	Above \$100,000–\$250,000 lifetime corpus	Mid-range and growing; both vehicles coordinate well
Beneficiary working or earning	Important; ABLE-to-Work adds supplemental tier	Less important; SNT does not depend on earnings	Earned income flows to ABLE, gifts and insurance to SNT
Spending pattern	Routine, discretionary, beneficiary-managed (food, transit, electronics)	Discretionary, trustee-managed (vacations, therapies, major equipment)	Day-to-day spending from ABLE; trustee-managed for larger items
Beneficiary cognitive capacity to manage account	Higher; beneficiary can directly access ABLE debit card	Lower or variable; trustee makes distributions	Mixed; both available as capacity changes over time

Decision input	ABLE alone	SNT alone	Both
Estate-recovery concern at death	ABLE balance is subject to Medicaid payback in most states	Third-party SNT has no payback; first-party SNT does	Plan to spend down ABLE balance and preserve third-party SNT for inheritance to remainder beneficiaries

Source: 26 U.S.C. § 529A; 42 U.S.C. § 1396p(d)(4); SSA POMS SI 01130.740 and SI 01120.203; ABLE National Resource Center planning guides.

Source: 42 U.S.C. § 1396p(d)(4)(A) and (d)(4)(C); Social Security Program Operations Manual System (POMS) SI 01120.203.

ABLE accounts — the working companion to the trust

~5 min read

ABLE accounts (Achieving a Better Life Experience, IRC § 529A) are tax-advantaged savings accounts for individuals whose disability onset occurred before age 26 — a threshold raised to age 46 effective January 1, 2026 under the ABLE Age Adjustment Act, materially expanding eligibility to millions of additional adults whose disability onset was between 26 and 46. Earnings grow tax-free when used for qualified disability expenses, and assets in an ABLE account are excluded from SSI's \$2,000 countable-asset limit up to a \$100,000 safe harbor. State ABLE plans vary in lifetime maximum, fees, and whether contributions qualify for a state income-tax deduction; Appendix A lists the plan name and tax-advantage status for each of the fifty states and the District of Columbia.

2026 contribution mechanics

Limit	2026 amount	Note
Annual contribution (all sources)	\$19,000	Indexed to the federal gift-tax annual exclusion. Combined across all contributors.
ABLE-to-Work supplemental (employed beneficiary)	Up to \$15,650 add'l	Equal to lesser of beneficiary's earned income or the federal poverty line for a one-person household. Available only if beneficiary is not contributing to an employer retirement plan.
SSI countable-asset safe harbor	\$100,000	ABLE balance up to \$100,000 excluded from the \$2,000 SSI resource limit. Balance above \$100,000 counted; SSI suspended (not terminated) while exceeded.
Medicaid eligibility — ABLE balance	No cap	Entire ABLE balance, including amounts above the \$100,000 SSI safe harbor, is excluded for Medicaid eligibility purposes.
Lifetime maximum (state-plan dependent)	Typically \$300K–\$550K	Set by each state plan, generally tied to that state's 529 college-savings account maximum. See Appendix A for the maximum applicable to your state's plan.

Source: IRS Notice 2025 indexing release; 26 U.S.C. § 529A; individual state ABLE program rules; SSA POMS SI 01130.740.

Qualified disability expenses

The definition is broad on purpose. Any expense that maintains or improves the beneficiary's health, independence, or quality of life qualifies, including:

- Housing (with care — see callout below)
- Education, including tuition, books, and tutoring
- Transportation, including vehicle purchase, modification, and operating costs
- Employment training and support

- Assistive technology and personal-support services
- Health, prevention, and wellness expenses not covered by insurance
- Financial-management and administrative services
- Legal fees
- Funeral and burial expenses
- Basic living expenses

WORKED EXAMPLE

When ABLE beats writing the parental check

Setup. A 24-year-old beneficiary works part-time at a grocery store earning \$14,000/year, lives at home, and receives \$943/month in SSI. Parents want to help her buy a used car. **Wrong move.** Parents buy the car in her name and gift it; the \$11,000 purchase blows past the \$2,000 SSI countable-asset limit on day one. SSI is suspended; Medicaid coverage is at risk. **Right move.** Parents contribute \$11,000 to her ABLE account (well within the \$19,000 annual limit). She uses the ABLE balance to purchase the car — a qualified disability expense for transportation. The vehicle is owned by her but does not count against the \$2,000 limit because ABLE-funded assets retain their exclusion. Benefits continue uninterrupted. Net result: same gift, completely different benefit outcome.

The housing footnote

Housing expenses are qualified disability expenses for ABLE purposes, but housing paid from the ABLE account in the *same month* it is withdrawn is treated as in-kind support and maintenance (ISM) by SSI, which can reduce the monthly SSI benefit by up to one-third. The fix is operational: withdraw the housing amount and pay the housing bill in the same calendar month, never let the funds sit. The Special Needs Alliance and most ABLE administrators publish step-by-step procedures.

Source: SSA POMS SI 01130.740 D; ABLE National Resource Center FAQ on housing expenses (ablenrc.org).

Letter of Intent — the document that outlives you

~4 min read

This is the letter your child can never read, written to the people who will care for them when you cannot. The trust says where the money goes. The Letter of Intent says how the person should be cared for. It has no legal force. It is, in most families, the single most important document the parents will ever write, and the one most likely to be missing when it is needed.

A Letter of Intent is a narrative document, updated annually, that captures everything a future caregiver — a sibling stepping in, a professional guardian, a successor trustee, a group-home staff member — would need to know to continue the life the parents have built. It should be specific, current, and stored where the successor trustee and the named guardian both know to find it.

SELF-ADVOCATE VOICE

“The Letter is for me too. I want to help fill it in. The people who will care for me later should know what I love, not just what my parents think I love. We do this together.”

— An adult self-advocate on the Letter of Intent

What a complete Letter of Intent covers

Section	What to include
Daily routine	Wake time, bedtime, mealtimes, favorite foods, food sensitivities and allergies, hygiene preferences, screen-time limits.
Medical	Diagnoses (current), medications and dosing schedule, allergies, treating physicians and specialists with contact info, insurance details, advance directives, hospital preferences, prior reactions to medications.
Behavioral triggers	What upsets the beneficiary, what calms them, sensory sensitivities, warning signs of distress, de-escalation techniques that work, situations to avoid.
Communication	How the beneficiary expresses needs (verbal, sign, AAC device, behavioral), comprehension level, important phrases to use or avoid.
Social network	Friends and their families, regular activities (faith community, day program, Special Olympics, sports, clubs), people who matter, people to keep at a distance.
Education / vocation	Current program, IEP / 504 history, vocational goals, work history, employer contacts if employed.
Religious / spiritual	Faith tradition, congregation, clergy contacts, rituals or practices important to the beneficiary.
Recreation and joy	What the beneficiary loves — the music, the team, the book, the trip, the food. The things a stranger would not know to provide.

Section	What to include
End-of-life wishes	Both for the beneficiary (medical preferences, organ donation, funeral, burial) and parents' wishes for how to communicate news of their own deaths.
Financial overview	Where the trust documents are, who the attorney is, who the tax professional is, who the trustee is, banking and benefit-deposit details.

WHY THIS MATTERS

Re-read the letter every year on the same date

Schedule it: the parents' wedding anniversary, the beneficiary's birthday, January 1, whatever sticks. Re-reading forces revision. Medications change. Doctors retire. Friends move. A five-year-old Letter of Intent is a museum piece, not a working document. A current one is a gift to whomever steps in.

A blank Letter of Intent — the sample template

~8 min read

What follows is a section-by-section template the parents can copy into a word processor and fill in. There is no required length. A two-page Letter of Intent is better than a missing one; a thirty-page Letter of Intent that has not been updated in seven years is worse than a current two-pager. Fill what you know. Leave the rest blank and come back. The trustee and successor guardian both need to know where this document is stored.

Header — identification

Field	Fill in
Beneficiary's full legal name	_____
Date of birth / SSN (last 4)	_____
Current residence address	_____
Date this letter was last updated	_____
Author(s) of this letter	_____
Where the original is stored	_____
Successor trustee — name + contact	_____
Named guardian (if any) — name + contact	_____

Section 1 — Daily routine

Wake time, bedtime, mealtimes, food preferences and dislikes, food allergies and sensitivities, hygiene routines, dressing preferences, screen-time pattern, comfort objects, sleep aids, weekly rhythm (school days vs. weekends, religious observance, day-program schedule). Be specific about what calms the beneficiary at the end of a hard day.

Section 2 — Medical

Current diagnoses (with dates), current medications and dosing schedule, drug allergies, treating physicians and specialists (name, practice, phone, portal login if shared), insurance details (carrier, policy number, plan year), Medicaid identification, dental and vision history, advance directives, preferred hospital, prior adverse reactions, pending referrals or appointments.

Section 3 — Education and vocational

Current school or day program (with contacts), IEP / 504 plan history and current goals, related-services schedule (speech, OT, PT, ABA), academic strengths and accommodations that work, vocational goals, any current employer or supported-employment program (with job-coach contact), transition-plan summary if age 14+.

Section 4 — Communication and behavior

How the beneficiary expresses needs (verbal, sign, AAC device, behavioral cues), comprehension level, phrases that help, phrases to avoid, known triggers, sensory sensitivities (lights, sound, texture, crowds), early warning

signs of distress, de-escalation techniques that have worked, situations to avoid entirely. If a Behavior Support Plan exists, reference where it is stored.

Section 5 — Social network and relationships

Friends and their families (with parents' phone numbers), faith community, regular activities (Special Olympics, day program, choir, Scouts), people who matter and should remain in the beneficiary's life, people to keep at a distance, sibling relationships and any expectations placed on a sibling.

Section 6 — Recreation and joy

What the beneficiary loves — the music, the team, the show, the book, the trip, the food. The things a stranger would not know to provide. What makes a birthday feel like a birthday. The pattern of a good weekend.

Section 7 — Religious and spiritual

Faith tradition, congregation name and clergy contact, rituals or practices that matter to the beneficiary, holiday observances, preferences around participation level (full participant, observer, non-participant).

Section 8 — Values and final wishes

What the parents most want preserved about the beneficiary's life: the priorities — independence, community presence, family contact, specific traditions. End-of-life preferences for the beneficiary (medical-decision style, organ donation, funeral, burial / cremation). How the parents wish news of their own death communicated to the beneficiary, and by whom.

Section 9 — Financial and document map

Where the trust documents are, who the attorney is (firm, contact), who the tax practitioner is, who the trustee and successor trustees are, banking and benefit-deposit details, ABLE plan and login, life insurance carrier and policy numbers, where the Letter of Intent itself is stored (and any digital copy).

WORKED EXAMPLE

How to start when starting feels impossible

Setup. Parents of a newly-diagnosed 6-year-old. The full template feels overwhelming. **What works.** Take a Sunday afternoon. Fill in the Header and Section 1 (daily routine) only. Stop there. Save the file. Mark a date 90 days out on the calendar. On that date, add Section 2 (medical) — the parents already know it, they just need to write it down. Continue at 90-day intervals until the document is complete. Then re-read annually on the same date. Most families who try to do this in one sitting never finish. Most families who do it section by section finish in under a year.

Three Letter-of-Intent scenarios — what they look like in practice

~10 min read

Below are three short, illustrative scenarios — fictional families, realistic situations — showing how the same template adapts to different diagnoses, ages, and family configurations. Each scenario shows only the parts of the letter that vary most by situation; the header and document-map sections are essentially the same across all three.

Scenario A — Parents writing for a 4-year-old with autism and developmental delays

Family. Two-parent household. Younger sibling, age 2 (typically developing). Diagnosis confirmed at age 3. Currently in an early-intervention preschool program; pending IEP transition to kindergarten.

What the letter emphasizes. Daily routine in fine detail — the bedtime sequence (bath, two books, weighted blanket, hallway light on, door cracked four inches), specific food textures the child accepts and the half-dozen she will not touch, the calming script after a meltdown, the early-warning signs that precede a meltdown by ten minutes if anyone is paying attention. The medical section is short — pediatrician, developmental pediatrician, speech therapist, OT — but the communication section is the longest in the letter, because the child uses about forty words and an AAC tablet, and a successor caregiver needs the full vocabulary.

What the letter notes about siblings. The parents explicitly place no expectation on the younger sibling to serve as future trustee or primary caregiver; they name a maternal aunt as successor trustee and document the conversation in which the aunt agreed.

Scenario B — Aging parents (ages 71 and 68) writing for an adult son (age 38) with Down syndrome

Family. Adult son lives at home; works 18 hours per week at a supported-employment grocery position; one sister, age 35, married, two children. Parents have an existing third-party SNT funded by a second-to-die policy.

What the letter emphasizes. Continuity of the son's adult life after the parents are gone — his work, his Special Olympics swim team, his weekly Friday dinner at the parish, his three closest friends and their families. The medical section is detailed: hypothyroidism, mild OSA managed with CPAP, annual cardiology screening, current dentist (who specializes in patients with Down syndrome). The communication section is short — the son is fully verbal — but the behavior section notes specifically how he handles grief and how the parents wish news of their deaths to be delivered (by the sister, in person, at home, with a familiar object from the parent — the father's watch, the mother's rosary — given at the same time).

What the letter notes about residence. The parents have explored a nearby intentional-community group home and toured it twice with their son. The letter records the son's reaction (positive on the first visit, anxious on the second, comfortable by the third) and the parents' guidance: try the group home for six months after their deaths, but if the son is unhappy, the sister has discretion as successor trustee to fund a different living arrangement.

Scenario C — Parents writing for a 12-year-old with medical complexity (cerebral palsy, seizure disorder, G-tube)

Family. Single mother; older brother, age 16; the child requires near-continuous medical management. Twelve specialists across three hospital systems. Mother is the primary care coordinator and has memorized the medication schedule.

What the letter emphasizes. The medical section is the longest in the letter and is structured as an operations manual: the medication schedule by hour, the seizure protocol (what counts as rescue-meds territory, what counts as 911 territory, who to call at the neurology service), the G-tube feeding schedule and the formula preparation steps, the equipment vendors and their phone numbers, the DME contacts, the hospital-system MyChart logins. The letter notes which specialists are willing to take a phone call from a successor caregiver and which require an in-person visit.

What the letter emphasizes about the brother. The mother is explicit that the older brother is not to be the primary caregiver — he will be 20 when the mother's own life expectancy starts to factor in, and the letter names a professional fiduciary as successor trustee. The brother is named as a co-trustee with limited authority over recreation and family-relationship distributions only.

WHY THIS MATTERS

These three letters are very different, on purpose

There is no template-perfect Letter of Intent — there is only the letter that *your* beneficiary's successor caregiver will need. The blank template above is a scaffolding. The scenarios above show how three families with different situations filled the same scaffolding differently, emphasizing what their beneficiary's life actually requires.

Trustee selection and the two-tier funding strategy

~5 min read

Choosing a trustee

Option	Strengths	Weaknesses
Family member (sibling, relative)	Knows the beneficiary; emotional commitment; low cost.	Mortality and capacity risk; possible family conflict; rarely fluent in trust accounting and benefit rules.
Professional individual (attorney, CPA, fiduciary)	Technical competence; continuity within firm; objective.	Cost; depth of relationship with beneficiary varies; succession within firm not guaranteed.
Corporate trustee (bank, trust company)	Institutional continuity; regulated; deep operational capacity.	Higher cost; minimum-asset thresholds (often \$250K–\$1M); risk of impersonality.
Pooled-trust nonprofit	Disability expertise; institutional; works for smaller corpora.	Distribution policies set by trust, not family; remainder share at death.
Co-trustees (family + professional)	Combines warmth with competence; check-and-balance.	More expensive than family-only; requires clear delineation of authority.

WHY THIS MATTERS

Name at least two successors

The single most common trust-administration failure is a named trustee predeceasing the parents with no successor. Every SNT should name a primary trustee, a first successor, a second successor, and a mechanism (often a trust-protector clause) for naming further successors thereafter. Review the chain every five years.

The two-tier funding strategy

Most families cannot fund the full lifetime corpus of an SNT during the parents' working years — nor should they try. The widely used approach is two-tiered:

Tier 1 — During parents' lives. Fund the SNT gradually with tax-deductible-where-possible contributions, grandparent gifts, and windfalls (bonuses, inheritances received by parents, business-sale proceeds). The goal is not full funding; the goal is a working corpus of \$25,000–\$100,000 that allows the trustee to step in immediately if a parent becomes incapacitated.

Tier 2 — At parents' deaths. A second-to-die life insurance policy, owned by an Irrevocable Life Insurance Trust (ILIT) or by the SNT itself, delivers the bulk of the lifetime corpus when both parents are gone. The math — how much insurance, what type, projected to what age — is in Part III.

Source: Special Needs Alliance position papers on funding the special needs trust (current edition, specialneedsalliance.org); AICPA Disability Planning Practice Guide (current edition).

PART II**Preserving Benefits While Building Wealth**

The legal architecture in Part I exists to do one thing: let the family build wealth for the beneficiary without disqualifying them from public benefits that are otherwise impossible to replace privately. Part II is the eligibility math, the state-waiver framework, and the most common ways well-meaning families accidentally cost their child years of coverage.

SSI, SSDI, and Medicaid — the eligibility math

~8 min read

Three federal programs do most of the work, and they interact in ways that surprise most families on first encounter. Understand each one on its own, then read the interaction notes.

Supplemental Security Income (SSI)

SSI is a means-tested cash benefit for individuals who are aged, blind, or disabled and who have very limited income and resources. It is funded by general tax revenue, not by Social Security taxes. In most states, SSI eligibility automatically establishes Medicaid eligibility — which is usually the more economically important benefit. A handful of states (the so-called “209(b) states”) use their own Medicaid eligibility criteria; consult Appendix A for your state's Medicaid agency and confirm whether SSI receipt alone establishes Medicaid in your jurisdiction.

SSI 2026 figure	Amount
Federal benefit rate — individual (monthly)	\$967
Federal benefit rate — couple (monthly)	\$1,450
Countable resource limit — individual	\$2,000
Countable resource limit — couple	\$3,000
General income exclusion (monthly)	\$20
Earned income exclusion (monthly, plus 50% above)	\$65
Substantial Gainful Activity (SGA) — non-blind (monthly)	\$1,620
Substantial Gainful Activity (SGA) — blind (monthly)	\$2,700

Source: Social Security Administration, 2026 SSI Federal Payment Amounts and Cost-of-Living Adjustment notice; SGA thresholds per 20 C.F.R. § 404.1574 and SSA annual update.

Social Security Disability Insurance (SSDI)

SSDI is an insurance program funded by Social Security payroll taxes. Eligibility is based on the recipient's (or a deceased or retired parent's) work history, *not* on income or assets. A disabled adult child (DAC) of a retired, deceased, or disabled parent who became disabled before age 22 can collect SSDI on the parent's earnings record — often a far larger monthly benefit than SSI. SSDI carries Medicare (after a 24-month waiting period), not Medicaid; many families end up dual-eligible.

Medicaid

Medicaid is a joint federal-state program providing health coverage and, critically, long-term services and supports (LTSS) that private insurance almost never covers — day programs, in-home aides, group homes, respite care. For most special-needs families, Medicaid is the irreplaceable benefit. The dollar value of lifetime Medicaid LTSS for an adult with significant disability typically exceeds the value of every other planning vehicle combined.

The 209(b) states — where SSI does not automatically establish Medicaid

Most U.S. states are “1634 states” in which receipt of SSI automatically establishes Medicaid eligibility. Ten states elected, under Section 209(b) of the Social Security Amendments of 1972, to use their own (and often more restrictive) Medicaid eligibility criteria. In a 209(b) state, an SSI recipient may still need to file a separate Medicaid application and meet the state's own income, asset, or medical-need tests. Per the current SSA list, the ten 209(b) states are:

- Connecticut
- Hawaii
- Illinois
- Minnesota
- Missouri
- New Hampshire
- North Dakota
- Ohio
- Oklahoma
- Virginia

Families in any of these states should confirm Medicaid eligibility directly with the state Medicaid agency (Appendix A) rather than assuming SSI enrollment is sufficient. Counsel licensed in a 209(b) state should be specifically asked about the state's spend-down, income-disregard, and medically-needy pathways.

Source: Social Security Administration Program Operations Manual System (POMS) SI 01715.010 (Medicaid and the Supplemental Security Income (SSI) Program); state list current as of 2026 — confirm with SSA before relying.

Spousal-impoverishment rules — protecting the well spouse

When a married couple has one spouse who needs long-term-care Medicaid (most commonly an aging parent of a special-needs adult), federal spousal-impoverishment rules (42 U.S.C. § 1396r-5) let the well spouse retain a **Community Spouse Resource Allowance** (approximately \$157,920 in 2026, indexed annually) and a **Minimum Monthly Maintenance Needs Allowance** for living expenses. The home, one vehicle, and certain other resources are additionally excluded. These rules matter for special-needs families because the same parents who fund the SNT may themselves need LTC Medicaid in their seventies or eighties — and a careless

asset transfer in the prior five years can disqualify them. Coordinate the parents' own Medicaid planning with counsel experienced in elder law alongside the special-needs planning; the two regimes overlap and the lookback periods interact.

Source: 42 U.S.C. § 1396r-5; CMS State Medicaid Manual; annual spousal-impoverishment thresholds published by CMS.

WHY THIS MATTERS

Protect Medicaid first, optimize the rest later

When the eligibility math gets complicated, default to the choice that preserves Medicaid LTSS access. A few hundred dollars of monthly SSI is replaceable from the trust. Twenty years of group-home placement and day-program funding is not.

State Medicaid waivers — the §1915(c) framework

~6 min read

Most U.S. states deliver long-term services and supports for individuals with developmental, intellectual, or physical disabilities through Medicaid Home- and Community-Based Services (HCBS) waivers authorized under Section 1915(c) of the Social Security Act. The federal framework is uniform; each state designs its own waiver(s) within it, with its own name, target population, slot count, and waitlist. The principle is that the waiver allows the state to fund community-based supports (group homes, in-home aides, day programs) as an alternative to institutional placement.

Representative state waivers (illustrative)

State / waiver	Target population	Notes
California — In-Home Supportive Services (IHSS) and DDS regional center waiver	Individuals with developmental disabilities; aged, blind, and disabled needing in-home care.	Regional centers (21 statewide) coordinate eligibility and service planning. Generally entitlement-style for eligible individuals — limited waitlist.
Texas — STAR+PLUS, HCS, CLASS, MDCP	STAR+PLUS for adults with disability; Home and Community-based Services (HCS) for developmental disability; Community Living Assistance and Support Services (CLASS) for physical disability.	Multi-year interest-list waits common, particularly for HCS.
New York — OPWDD HCBS Waiver	Individuals with intellectual / developmental disability served through the Office for People With Developmental Disabilities.	Front-door process via OPWDD eligibility; some service tracks generally available, others waitlisted.
Florida — iBudget Florida (APD)	Individuals with developmental disabilities (intellectual disability, autism, cerebral palsy, spina bifida, Prader-Willi, Down syndrome).	Multi-year statewide waitlist; crisis-enrollment exceptions narrow.
Illinois — DRS Home Services and DDD HCBS	Individuals with disability served through Division of Rehabilitation Services (DRS) and Division of Developmental Disabilities (DDD).	PUNS (Prioritization of Urgency of Need for Services) database determines selection from the developmental-disability waiting list.
Pennsylvania — Office of Long-Term Living and ODP waivers	Multiple waivers operated by Office of Developmental Programs (ODP) and Office of Long-Term Living (OLTL).	Consolidated, Community Living, and P/FDS waivers serve developmental-disability populations with differing service intensities.

STATE/LOCAL RESOURCE

Get on the waitlist the day the diagnosis is documented

Across nearly every state, the waiver waitlist is the single longest-running clock in the family's planning life. Placement on the list is typically set by the submission date, not by need severity (except in narrow crisis-enrollment categories). The earliest practical step a family can take is filing the application as soon as the qualifying diagnosis is on the record — often by age 3. Find your state's developmental-disability agency contact in Appendix A.

Crisis enrollment

Most states allow out-of-turn enrollment for individuals in documented crisis — imminent risk of homelessness, parental death or incapacity, abuse, or institutionalization. The criteria are narrow and the documentation requirements are extensive. Families navigating crisis enrollment almost always benefit from a waiver-experienced advocate or attorney.

The HCBS Final Rule — what counts as a community setting

In 2014, the Centers for Medicare & Medicaid Services finalized the Home and Community-Based Services Settings Rule (42 C.F.R. § 441.301(c)(4)), often called the “HCBS Final Rule.” The rule requires that any setting receiving HCBS waiver funding be *integrated in and support full access to* the broader community: residents must be able to choose their roommates, control their schedules, have visitors of their choosing, access the community, and have privacy in their own bedrooms. Settings that are institutional in character (isolated campuses, gated developmental-disability communities, group homes operated with regimented schedules) are presumptively non-compliant and must demonstrate otherwise.

For families, the practical implication is that the universe of Medicaid-fundable adult living arrangements has been narrowed and redefined since 2014. Some traditional group homes and intentional-community models had to restructure (or lost waiver funding) to qualify. Others — supported living, host-home, shared-living — became more available. State implementations vary; verify with the state developmental-disability agency (Appendix A) and any prospective housing provider that the setting is fully HCBS-compliant before relying on Medicaid funding.

Source: 42 C.F.R. § 441.301(c)(4); CMS HCBS Settings Final Rule guidance and state transition plans ([medicaid.gov/hcbs](https://www.medicicaid.gov/hcbs)).

Medicaid Buy-In — for working adults with disabilities

Most U.S. states operate a Medicaid Buy-In program (also called “Medicaid for Working People with Disabilities” or MWPD) under Section 1619(b) of the Social Security Act and related state buy-in authorities. The program lets working adults with disabilities earn substantially above the traditional SSI limit while retaining Medicaid coverage, typically by paying a sliding-scale premium based on income. The income ceilings, premium scales, and asset limits vary by state, but in many states a beneficiary can earn \$40,000 to \$75,000 or more per year and still keep Medicaid.

Medicaid Buy-In is the right answer for a beneficiary who wants to work meaningfully — full-time or substantially full-time — without losing the LTSS coverage that no private insurer reliably replaces. Coordinate with a WIPA counselor before any significant change in work hours: the math interacts with SSI, SSDI, ABLE-to-Work contributions, and the state's specific buy-in rules. Find the state Medicaid agency contact in Appendix A.

Source: Section 1619(b) of the Social Security Act; state-specific Medicaid Buy-In and MWPD program rules; SSA POMS SI 02302 series.

Source: Section 1915(c) of the Social Security Act; Centers for Medicare & Medicaid Services HCBS Waiver program documentation; individual state-agency operating procedures.

The \$2,000 trap, earned income, and the inheritance landmine

~6 min read

The \$2,000 countable-asset trap

An SSI recipient cannot hold more than \$2,000 in countable resources (home, one vehicle, and certain other items are excluded). The number has not changed materially since 1989. It is the most common cause of benefit termination, and it almost always traces to one of three events: a gift, an inheritance, or accumulated savings.

- **Gift.** A grandparent transfers cash directly to the beneficiary's bank account. Once the balance crosses \$2,000, SSI is suspended. *Fix:* route the gift to the SNT or ABLE.
- **Inheritance.** A relative dies and names the beneficiary on a beneficiary form (life insurance, IRA, brokerage account). The money lands in the beneficiary's name. *Fix:* the inheritance must be redirected, typically into a first-party d4A trust, which carries Medicaid payback — the worst-case scenario the family was trying to avoid.
- **Accumulation.** The beneficiary works part-time and saves. *Fix:* sweep earnings to ABLE up to the annual limit; balance above the SSI safe-harbor goes to the third-party SNT.

WORKED EXAMPLE

The grandparent landmine and the fix that prevents it

Setup. Grandfather, age 78, has \$200,000 in a brokerage account and wants to leave \$50,000 to his disabled adult grandson, currently receiving \$943/month SSI and Medicaid LTSS worth \$54,000/year through his state's HCBS waiver. **What goes wrong.** Grandfather names the grandson directly as a 25% beneficiary on the brokerage form. He dies; \$50,000 lands in the grandson's name. SSI and Medicaid suspend. The family scrambles to set up a d4A first-party trust within the month, which works — but the \$50,000 now carries lifetime Medicaid payback. At grandson's death decades later, the state recovers (potentially) the full \$50,000 plus growth. **What should have happened.** Grandfather works with counsel experienced in special-needs trust drafting to amend the beneficiary form to name the existing third-party SNT — not the grandson. The \$50,000 flows into the third-party trust, no payback, full preservation of benefits, no scramble. Drafting fee for the change is typically modest. Lifetime cost of getting it wrong: tens of thousands plus the family stress of an avoidable crisis. *The change must be drafted by counsel with special-needs trust experience licensed in the relevant state.*

Earned income and Substantial Gainful Activity

SSDI eligibility ends when the recipient earns above the Substantial Gainful Activity threshold (\$1,620/month for non-blind individuals in 2026, \$2,700 for blind). SSI uses a different and more forgiving formula: the first \$85 of monthly earnings is disregarded, and each dollar above that reduces the SSI check by 50 cents. A beneficiary can work substantially — sometimes \$20,000–\$30,000/year — while keeping at least a partial SSI check and full Medicaid. Work incentives such as the Plan to Achieve Self-Support (PASS) and Impairment-Related Work Expenses (IRWE) extend this further. The calculations are not intuitive; the SSA Red Book is the authoritative reference and a Work Incentive Planning and Assistance (WIPA) counselor can

run them for free.

Source: SSA Red Book (2026 edition); 20 C.F.R. § 416.1112; Ticket to Work program, WIPA service directory.

Tax planning for the special-needs family

~7 min read

Tax planning is not the headline benefit — preserving Medicaid and SSI is. But the U.S. federal tax code contains several provisions specifically intended to ease the financial burden of disability, and most families leave money on the table by not claiming them. Many states layer additional disability-related deductions or credits on top; consult a tax practitioner licensed in your jurisdiction with experience in §1917(d)(4)(A) trust accounting and Form 1041 grantor-trust reporting.

Provision	What it does	2026 amount / mechanic
Medical expense deduction (Schedule A)	Deduct unreimbursed medical and disability-related expenses above 7.5% of AGI. Includes therapies, special schooling (when medically necessary), travel for treatment, home modifications.	Itemized; threshold 7.5% of AGI.
Dependent Care Credit	Credit for care of a qualifying person (including a disabled adult dependent) to enable parents to work.	Up to \$3,000 expenses for one qualifying person; credit 20–35% based on AGI.
Child and Dependent Care benefits exclusion	Employer-provided dependent-care benefits up to the annual limit are excluded from gross income.	Up to \$5,000 per household (\$2,500 married filing separately).
Qualifying Child / Qualifying Relative	An adult child with disability who is permanently and totally disabled may remain a qualifying child regardless of age, providing a dependent exemption equivalent and HoH filing eligibility.	No age cap when permanent and total disability is established.
ABLE contribution — Saver's Credit	Working ABLE beneficiaries who contribute to their own ABLE may claim the Saver's Credit on those contributions.	Credit of 10/20/50% of contributions up to \$2,000, based on AGI.
Disability-related work expenses (IRWE)	For SSI/SSDI recipients, certain impairment-related work expenses reduce countable earned income for benefit-calculation purposes.	Calculated on a case-by-case basis.

WHY THIS MATTERS**Medical expense documentation is a year-round habit**

The 7.5%-of-AGI threshold is high, but families with significant therapy, special-school, or home-modification expenses routinely clear it. The lost-deduction risk is not eligibility, it is documentation. Keep a folder — paper or digital — for every receipt, mileage log, and prescription. At year-end, the deduction either materializes or it doesn't, but the folder is what makes it possible.

Source: IRC § 213 (medical expenses); IRC § 21 (Dependent Care Credit); IRC § 25B (Saver's Credit); IRC § 529A (ABLE).

PART III

Insurance and the Parents

The trust funded modestly during the parents' lives needs a delivery mechanism for the larger corpus at the second parental death. For most middle-income special-needs families, that mechanism is life insurance. Part III walks the funding math, the policy choices, and the parallel insurance decisions — disability, long-term care, health — that protect both the parents and the trust they are building.

Second-to-die life insurance funding the trust

~5 min read

A second-to-die (survivorship) policy pays out only on the death of the second insured. Premiums are lower than two separate single-life policies because the insurer is pricing the joint survival, and the policy is structured precisely for the moment the trust needs to be funded — when both parents are gone and the beneficiary's lifetime support shifts entirely to the trust corpus.

Term vs whole vs guaranteed universal life

Type	What it is	Fit for SNT funding
Survivorship term	Coverage for a fixed period (20–30 years). Lowest premium per dollar of death benefit. Expires worthless if both insureds outlive the term.	Rarely the right fit. Special-needs funding is a lifetime need; outliving the policy is the worst case.
Survivorship whole life	Permanent coverage; level premium; builds cash value. Higher premium; some flexibility via dividends and loans.	Strong fit when premium is affordable. Guaranteed death benefit, predictable funding.
Guaranteed Universal Life (GUL) — survivorship	Permanent coverage at a guaranteed level premium to a specified age (typically 100 or 121). Minimal cash value; lowest cost permanent option.	Often the best fit when the goal is a guaranteed death benefit at a known premium, with no need for cash value.
Variable / Indexed UL — survivorship	Permanent coverage with market-linked cash value. Premium and death benefit can fluctuate based on performance.	Higher complexity and risk; usually unnecessary when the goal is funding a trust at a known dollar amount.

WHY THIS MATTERS**Match policy duration to need duration**

The single most common life-insurance mistake in special-needs planning is buying term coverage to fund what is structurally a lifetime obligation. Term is appropriate for time-limited needs (mortgage, kids through college). The SNT corpus is not time-limited — the beneficiary will need support until their own death. Permanent coverage, even at higher premium, aligns the tool to the job.

Worked example — the funding calculation

~6 min read

Before the math: the inputs to this calculation are your own death and your child's life expectancy. Those are not actuarial categories to most parents — they are the two hardest sentences in this reference. Read this section once, set it down, come back to it. The discipline of running the numbers is, in the end, a form of love — the version of love that shows up as a funded trust when you are no longer here to show up in person. Verify life-expectancy assumptions with your child's treating physician; do not use planning-document averages for a real plan.

The funding question — “how much does the trust need at the second parental death?” — has four inputs: the supplemental support need in today's dollars, the years that support is required, the inflation assumption, and the projected portfolio return after the trust is funded.

WORKED EXAMPLE**A representative special-needs funding calculation**

Setup. Beneficiary is age 8. Parents both age 40. Beneficiary has a developmental disability with normal life expectancy of 65 (reasonable planning assumption for many diagnoses; verify with the treating physician). Public benefits (SSI plus Medicaid LTSS) are projected to cover essential medical and group-home placement. The trust supplements with quality-of-life expenses: vacations, recreation, the iPad upgrade, the additional therapies Medicaid won't fund, a private case-manager visit twice a month. Estimated supplemental need: **\$50,000/year** in today's dollars.

Assumptions. Inflation 3.0%. Trust portfolio long-term after-fee return 5.0%. Both parents projected to die between ages 85 and 90; planning assumption is second death at parent age 87 (beneficiary age 55). Trust must therefore support the beneficiary from age 55 to 65 — a 10-year tail.

Step 1 — inflate the annual need. \$50,000 today, grown at 3% for 47 years (parent 40 to parent 87) $\equiv \$50,000 \times (1.03)^{47} \approx$ **\$200,000/year** at second death.

Step 2 — present value of the 10-year tail. A 10-year annuity of \$200,000 growing 3% annually, discounted at 5%, is approximately **\$1.78 million** at the moment of second death.

Step 3 — add a reserve. Add 20% for longevity risk, unexpected medical costs, and trustee discretion buffer. Target death benefit: **approximately \$2.15 million.**

Step 4 — reduce for existing tier-1 funding. Family has already funded \$75,000 in the SNT during the parents' lifetimes. Grown at 5% for 47 years, that grows to roughly \$740,000 at the time of the second death. **Net new insurance need: ~\$1.4 million** (rounded). A survivorship GUL policy with a \$1.5 million face amount, guaranteed to age 100, is the typical match for this profile.

Reality check. Numbers move with diagnosis, state of residence, parental health and insurability, and household cash flow. The point of the exercise is not the specific dollar figure — it is the discipline of running the math before buying the policy. The Baratelli Institute's *SNT Funding Calculator* (see Part V) lets a family re-run this with their own inputs.

Source: Standard actuarial PV-of-annuity formula; inflation and return assumptions illustrative — verify with treating physician for life-expectancy assumption and with financial planner for return/inflation projections.

Worked example — single-parent household

The two-parent worked example above does not translate cleanly to a single-parent household. The single-life math is different, the second-to-die survivorship policy is not available, and the trustee and successor-trustee questions are heavier because there is no surviving co-parent to provide redundancy. This sub-section reruns the calculation for a representative single-parent family.

WORKED EXAMPLE

A single-parent funding calculation

Setup. Single parent, age 38, divorced. Beneficiary is age 6 with a developmental disability and a reasonable planning life expectancy of 60 (verify with treating physician). The other parent is alive but uninvolved and not part of the support plan. Supplemental annual need projected at **\$45,000/year** in today's dollars (slightly lower than the two-parent example because the single-parent household has already learned to run on less).

Assumptions. Inflation 3.0%. Trust portfolio long-term after-fee return 5.0%. Parent's planning death age is 82 (beneficiary age 50). Trust must therefore support the beneficiary from age 50 to 60 — a 10-year tail.

Step 1 — inflate the annual need. \$45,000 today, grown at 3% for 44 years $\equiv \$45,000 \times (1.03)^{44} \approx$ **\$165,000/year** at the parent's death.

Step 2 — present value of the 10-year tail. A 10-year annuity of \$165,000 growing 3% annually, discounted at 5%, is approximately **\$1.47 million** at the moment of death.

Step 3 — add a longevity reserve. 25% reserve (higher than the two-parent case because there is no surviving co-parent to course-correct). Target trust corpus at death: **approximately \$1.85 million.**

Step 4 — choose the insurance instrument. The second-to-die survivorship policy that anchored the two-parent example is unavailable here. The single-parent toolkit is:

- *Term life* in the working years — large face amount (often \$1.5M—\$2M), 20- or 30-year level, owned by an Irrevocable Life Insurance Trust (ILIT) with the SNT as the named beneficiary. Term is appropriate *here* — not because the need is time-limited, but because the term policy is bridging to the years when retirement and other assets can fund the rest.
- *Permanent (GUL) layered above the term* for the portion of the need that extends past the term policy's expiration. A \$500K—\$750K GUL is a common companion.
- *Retirement-account beneficiary designation* naming the third-party SNT directly. The single parent has one retirement account, not two; the designation is more critical and the SECURE Act exception for disabled beneficiaries (eligible designated beneficiary status) preserves the stretch.

Step 5 — trustee redundancy. Single-parent households almost always require an extended-family or institutional trustee structure rather than relying on a single sibling. Build the co-trustee structure (family member + corporate trustee, or professional + protector) into the trust document from the start. Premium for the corporate trustee is the price of not leaving the succession to chance.

Reality check. Single-parent households often have less cash-flow flexibility, which makes the term-plus-GUL stack more common than survivorship policies in two-parent worked examples. The math principles do not change. The instrument selection does.

Source: Same actuarial framework as the two-parent example; single-life insurance pricing varies materially with parent's health and is the principal sensitivity in this calculation.

The full insurance stack for the special-needs family

~12 min read

A special-needs family's insurance program is not a single product — it is a layered stack of seven distinct coverages, each defending a different failure mode. Most families arrive at this section with one or two layers in place (typically health, sometimes term life) and discover gaps in the others. The discipline is to map each coverage to the risk it solves, then size each to the family's actual situation. The table below is the inventory; the sections that follow expand on each layer.

Coverage	Risk it solves	Typical owner / structure	When to put it in place
Second-to-die life insurance	Funds the bulk of the SNT at the second parental death — the moment when the parents' working income and direct caregiving both end.	Owned by an ILIT or by the SNT itself (depending on estate-tax exposure). Beneficiary is the SNT.	Once the SNT exists and the parents have stable cash flow. Underwriting is easier in the parents' 40s and 50s than later.
Term life on each parent	Bridges the gap between today and the second-to-die payout — if a single parent dies young, the survivor needs immediate liquidity.	Owned by each parent (or by the ILIT if estate-tax exposure exists). Beneficiary is the other parent or the SNT.	Immediately when the family is single-income-dependent, or anytime the parents are under 60 and the SNT is not yet fully funded.
Long-term disability (LTD) for working parents	Protects the income that funds the SNT — the most underrated coverage in the stack.	Individual policy with own-occupation definition; group LTD is a supplement, not a substitute.	While the parents are healthy and working — underwriting tightens with age and any diagnosis.
Long-term care insurance for parents	Prevents parents' end-of-life care costs from consuming the assets meant to fund the SNT.	Hybrid life/LTC policies preferred for the special-needs household; traditional LTC also acceptable.	Parents in their 50s; harder to underwrite past 65 and after major diagnoses.
Health insurance for the beneficiary	Continuous medical coverage through the disability-coverage transitions — parental plan, COBRA, ACA marketplace, Medicaid, Medicare.	Layered: parental plan (often indefinitely for disabled adult dependents), Medicaid via SSI, Medicare via SSDI after 24 months.	From birth, with active management at each transition (age 18, age 26, parental retirement, parental death).
Personal liability / umbrella insurance	Covers the family if the beneficiary or a caregiver causes injury or property damage — relevant especially in behaviors-of-concern households.	Personal umbrella over auto / homeowner; some carriers underwrite cognitive-disability households separately.	Once household assets exceed primary-coverage limits, or anytime a behaviors-of-concern profile creates above-baseline liability exposure.

Coverage	Risk it solves	Typical owner / structure	When to put it in place
Funeral / burial provision for the beneficiary	Pre-funds the beneficiary's eventual final expenses within SSI rules — \$1,500 of designated burial funds plus a pre-need burial contract are excluded resources.	Pre-need irrevocable burial contract with a licensed funeral home, plus a designated \$1,500 burial-fund account, plus a small life insurance policy on the beneficiary if insurable.	Mid-adulthood for the beneficiary, or earlier if the parents are aging out of the planning role.

Second-to-die life insurance — the funding cornerstone

Covered in depth in the worked example earlier in Part III. A survivorship policy (guaranteed-universal life is the most common structure) pays out at the death of the second parent, which is almost always when the SNT needs to be substantially funded. The policy is typically owned by an ILIT to keep the proceeds out of the parents' estates for federal and state estate-tax purposes, and the ILIT names the SNT as beneficiary. Two cautions: avoid letting the policy lapse into Modified Endowment Contract (MEC) status (which would tax internal growth at distribution); and be wary of premium-financing arrangements, which add interest-rate risk to a plan whose virtue is supposed to be stability.

Term life on each parent — the bridge layer

The second-to-die policy is built for the second death; a single parent's premature death is a different problem. A 20- or 30-year term policy on each parent, sized to replace the deceased parent's income through the survivor's working years and seed the SNT to a working balance, fills the gap. In single-income households this is non-negotiable — the working parent's income is the only thing keeping both household and SNT funding intact. In dual-income households the calculation is more nuanced but the answer is almost always: yes, on each parent. Term is inexpensive when purchased in the 30s and 40s; the cost climbs sharply after 55.

The Irrevocable Life Insurance Trust (ILIT)

A life insurance policy owned personally by a parent is included in that parent's gross estate at death. For most special-needs families this does not trigger federal estate tax (the 2026 federal exclusion remains in the multi-million range), but several states impose their own estate or inheritance taxes at lower thresholds; consult your state's tax authority for the applicable rules. The reason to use an ILIT is therefore part estate-tax planning and part controlling where the proceeds land and protecting them from creditors, divorce claims, and Medicaid estate recovery against the parents.

Typical structure: the ILIT is the policy owner and beneficiary. Parents make annual gifts to the ILIT trustee equal to the premium amount; the trustee sends Crummey notices to the beneficiaries (qualifying the gifts for the annual gift-tax exclusion) and pays the premium. At the second parental death, the death benefit flows from the ILIT to the SNT — or, in some designs, the ILIT and SNT are the same trust.

Disability insurance for the working parents

A disabled parent who cannot work threatens the entire funding plan. Long-term disability insurance (LTD) for the income-earning parent(s) is the underrated cornerstone of the architecture. Key features:

- **Own-occupation** definition of disability (pays if you cannot perform *your* profession, not *any* work).
- **Benefit period** to age 65 or 67 (not five years).
- **Residual / partial-disability rider** (pays a prorated benefit if disability reduces but does not eliminate income).
- **Cost-of-living adjustment** rider for benefits in payment.
- **Future-increase option** to raise coverage as income grows without re-underwriting.

Long-term care insurance for parents

If a parent enters nursing care, the cost of that care can consume the assets intended to fund the SNT — a single parent's five-year nursing-home stay at \$130,000/year (\$650,000) wipes out a significant portion of most families' net worth. LTC insurance, purchased while the parents are in their 50s, protects the funding plan against this scenario. Newer hybrid life/LTC policies provide LTC coverage with a death-benefit backstop if the LTC benefit is never triggered, which addresses the “use-it-or-lose-it” objection that historically slowed traditional LTC adoption.

Health insurance continuation for the disabled adult child

Health coverage for a disabled child is not a single decision — it is a sequence of handoffs over the lifetime, each of which is a potential gap. Most employer health plans permit indefinite coverage of a disabled adult child as a dependent provided disability was established before the policy's standard dependent-age cutoff (typically 26) and the child remains primarily dependent on the parent — the federal floor is set by ERISA § 609(c) and the ACA's age-26 requirement, and many states layer additional protections on top. When the parent retires or loses coverage, the handoff options include COBRA continuation (up to 36 months for qualifying events), the ACA marketplace (which cannot deny coverage for pre-existing conditions and may carry significant subsidy if household income drops), Medicaid (via SSI or state buy-in programs), and Medicare (after 24 months of SSDI receipt — a federal entitlement that begins on the disabled adult child's own work record or on a deceased / retired / disabled parent's earnings record).

Dual-eligible (Medicare + Medicaid) status is common in this population and is generally favorable — Medicare covers acute care; Medicaid covers long-term services and supports; many states operate integrated managed-care plans for dual-eligibles that simplify the experience. The handoffs between these coverages are where families lose weeks or months of coverage; map each transition out in advance with counsel familiar with special-needs planning and with the local State Health Insurance Assistance Program (SHIP) office, which offers free counseling on Medicare and dual-eligible coordination.

Personal liability and umbrella coverage

Households that include a beneficiary with behaviors-of-concern — elopement, property damage, occasional aggression — carry a higher-than-baseline liability exposure that is not always visible until something happens. A personal umbrella policy (sitting above primary homeowner and auto coverage) of \$1 million to \$5 million is inexpensive in absolute terms and protects both the parents' assets and the eventual SNT corpus from a single bad day. Disclose the household composition fully at underwriting; some carriers exclude cognitive-disability households or apply special endorsements, and the family is better served by knowing this up front than by discovering it at claim time. The Special Needs Alliance and a few national brokerages publish guidance on carriers that underwrite this population without unusual exclusions.

Funeral, burial, and the SSI burial-fund rules

An SSI recipient may set aside up to \$1,500 in a clearly designated burial-fund account without counting it against the \$2,000 resource limit, and a pre-need irrevocable burial contract with a licensed funeral home is fully excluded from countable resources (no dollar cap on the contract). The combination of these two — a \$1,500 burial-fund account plus a pre-need contract covering casket, services, and burial plot — pre-funds the beneficiary's final expenses inside the SSI rules, without depleting the SNT, without burdening surviving siblings, and without forcing a Medicaid-payback calculation at death. Many funeral homes maintain pre-need specialists familiar with SSI-compliant structures; the state funeral-services regulatory authority is the verification source for the licensure and consumer-protection regime in the relevant state. A small life insurance policy on the beneficiary (if insurable) owned by the SNT can supplement.

Source: ERISA § 609(c) (disabled adult child coverage); IRC §§ 2042, 2503 (ILIT estate inclusion and Crummey gifts); ACA § 1311; SSA POMS SI 01130.410 (burial funds) and SI 01130.420 (burial spaces).

PART IV

Life-Stage Map

What to do, in what order, at each stage of the beneficiary's life and the parents'. Use this section as a checklist. Each stage's tasks assume the foundational documents in Part I exist; if they don't, stop and build them first.

Birth to 18 — diagnosis through high school

~4 min read

The early years are about establishing infrastructure: documenting diagnosis, opening the right accounts, getting on the right waitlists, writing the first version of the Letter of Intent, and beginning to fund the trust.

- **At diagnosis.** Within 90 days, engage counsel licensed in your jurisdiction with documented special-needs trust experience. Establish the third-party SNT, even if it begins unfunded — the document needs to exist before grandparents update their estate plans.
- **Open an ABLÉ account** as soon as the diagnosis is on the record. ABLÉ has no minimum age; opening early establishes the account and builds tax-free growth runway. Compare your state's plan and other states' plans (most plans accept out-of-state residents) via the ABLÉ National Resource Center; see Appendix A for your state's plan name.
- **Apply for your state's HCBS waiver waitlist** the day the developmental-disability diagnosis is documented. State waitlists are the longest-running clocks in the family's planning life; placement on the list is typically set by submission date. See Appendix A for your state's developmental-disability agency contact.
- **Coordinate with the school.** IEP and 504 plans drive school-funded services that the family does not have to pay for directly. Track every IEP meeting outcome — it builds the documentation trail for adult-services eligibility later.
- **Grandparent gifting strategy.** Brief grandparents (and the counsel handling their estate plans) on the third-party SNT. Every gift, bequest, and beneficiary designation that touches the disabled grandchild should route through the SNT, not through the grandchild directly.
- **Start the Letter of Intent** by the child's 5th birthday. Update annually thereafter.
- **Tier 1 trust funding** begins as soon as cash flow permits — modest monthly contributions, holiday and birthday gifts redirected to the SNT, tax refunds.
- **Run the funding math** (Part III) by the child's 10th birthday. Apply for survivorship life insurance while both parents are insurable and premiums are lowest.

Turning 18 — what changes overnight

~6 min read

At age 18 your child becomes a legal adult. Several federal and state systems change overnight: parents lose default decision-making authority, SSI eligibility is recalculated on the adult's own income and resources (typically dropping the parent-income deeming that previously disqualified most working families), and the path to adult-services programs opens. Plan for this birthday at age 17, not at the birthday party.

- **Decision-making framework.** The choice is not simply “guardianship or not.” Every U.S. state recognizes a continuum, ordered here from least-restrictive to most-restrictive — choose the least-restrictive option that meets the young adult's actual decision-making needs: *supported decision-making agreement* (no court involvement; the adult chooses trusted supporters), *durable power of attorney with healthcare surrogate designation* (the adult delegates specific authority), *limited or partial guardianship* (court removes only specific rights), then *plenary or full guardianship* (court-ordered authority over all decisions; the most restrictive and the last option to consider). Federal disability-rights guidance treats supported decision-making as the presumptive starting point. Statutory names vary (Florida calls it “guardian advocacy” for adults with developmental disabilities; other states use “conservatorship” for property and “guardianship” for the person). Counsel licensed in your jurisdiction with special-needs trust and disability-rights experience can map the choices to the young adult's capacity.
- **SSI reapplication as an adult.** File at or shortly after age 18. The new application removes parental deeming; many beneficiaries who were ineligible as minors qualify as adults.
- **Adult Medicaid.** If SSI is approved, Medicaid follows automatically in most states (see Appendix A for any 209(b)-state distinctions).
- **HCBS waiver revisit.** If the family is not yet through the state waitlist, document the transition; in some cases the change in living arrangement at 18 affects priority.
- **ABLE-to-Work eligibility.** Once the beneficiary has any earned income, they qualify to make supplemental ABLE contributions above the annual limit. Coordinate with employer to avoid simultaneous employer-retirement contribution that disqualifies the supplemental tier.
- **Vocational Rehabilitation.** Refer to your state's Division of Vocational Rehabilitation (or equivalent) for transition services — job coaching, training, assistive technology funding. See Appendix B for the state agency contact.
- **Letter of Intent** update reflecting adult medical providers, decision-makers, and benefit identifiers.
- **Trust review.** Confirm trustee succession and confirm distributions to the now-adult beneficiary are correctly structured against SSI in-kind support rules.

STATE/LOCAL RESOURCE

Vocational rehabilitation is in every state

Every U.S. state operates a Division (or Department, Office, or Bureau) of Vocational Rehabilitation that conducts intake assessments and develops Individualized Plans for Employment (IPE) for adults with disabilities. Services typically include assessment, training, assistive technology, job placement, and supported employment. Application is free and does not require SSI or Medicaid eligibility, though service intensity is shaped by the beneficiary's capacity and goals. Find your state's agency in Appendix B.

Supported Decision-Making — the less-restrictive alternative

Supported Decision-Making (SDM) is the formal less-restrictive alternative to guardianship. In an SDM arrangement, the adult with a disability identifies one or more trusted supporters — parents, siblings, friends, a service-coordinator — who help with specific categories of decisions (medical, financial, vocational, housing) while the adult retains full legal authority. Supporters do not sign for the adult; they help the adult understand options and consequences, and then the adult signs. SDM is grounded in the same disability-rights principle behind the HCBS Final Rule and the Americans with Disabilities Act: the least-restrictive setting that meets the person's actual support needs.

A growing number of U.S. states have enacted SDM statutes that give the agreement formal legal recognition (so a hospital, bank, or school must honor it). Current statutory states include Texas (the first, 2015), Delaware, Wisconsin, Rhode Island, Nevada, Alaska, Indiana, North Dakota, North Carolina, Virginia, Maine, Louisiana, Colorado, Missouri, Massachusetts, the District of Columbia, and others. The list expands almost every legislative session; confirm current status with counsel in your jurisdiction or the National Resource Center for Supported Decision-Making (supporteddecisionmaking.org), which maintains a current state map and template agreement language.

SDM is not appropriate for every adult — some beneficiaries truly need plenary guardianship for their own safety. The point of the continuum in the bullet above is to start at the least-restrictive option and step up only as the documented decision-making record requires. Federal disability-rights guidance, the American Bar Association, and most state Protection & Advocacy systems (Appendix A) treat SDM as the presumptive starting point.

SELF-ADVOCATE VOICE

“I picked who helps me. My mom helps me with doctors. My friend helps me at work. I still sign my own name. Guardianship would have made me feel like a child. I am not a child.”

— A 22-year-old with Down syndrome, reflecting on her SDM agreement

Source: National Resource Center for Supported Decision-Making (supporteddecisionmaking.org); American Bar Association Commission on Law and Aging; state SDM statutes vary — verify current status with counsel licensed in your jurisdiction.

Adult years — 19 to 50

~6 min read

The adult years are the longest stretch and the one most likely to be navigated without parental involvement — because at some point in this window, the parents will retire, become ill, or die. The infrastructure built in earlier stages is what carries the beneficiary through.

Employment and benefits

Employment is supported, not optional-by-default. Even modest earnings build self-worth, social network, and ABLE balance. Coordinate with a WIPA (Work Incentives Planning and Assistance) counselor before any significant change in hours or wage. PASS plans can shelter earnings for an explicit work goal (education, vehicle, business startup) without affecting SSI.

Housing

Option	Funding source	Notes
Continued family home	Parents (or SNT after parental death)	Most common in early adult years; sustainability depends on parental health and trust funding.
Group home	HCBS waiver covers staffing; rent paid by beneficiary from SSI/SSDI	Mainstream answer for adults with significant support needs; placement dependent on waiver.
Supported living	HCBS waiver covers staffing; rent from SSI/SSDI	More independent than group home; suits beneficiaries with greater capacity and a smaller circle of needed supports.
Family-owned home, SNT-maintained	Home titled in third-party SNT; trust pays property taxes, repairs, insurance	Preserves Medicaid; allows beneficiary to remain in a familiar setting. Requires careful trustee management of ISM rules.
Section 8 / HUD subsidized	HUD voucher	Available; multi-year waitlists in most regions of the country.

Alternative housing models — beyond the traditional group home

Group homes are the default U.S. answer, but they are not the only answer, and for some beneficiaries they are a poor fit. A growing set of alternatives has emerged over the last forty years, with uneven state-by-state availability. Families researching options should ask the state developmental-disability agency (Appendix A) what each model looks like locally, since the same name can describe very different programs across state lines.

- **Microboards.** A microboard is a small (typically 5—8 person) nonprofit corporation organized specifically around one individual with a disability. The board includes family members, friends, and one or two unrelated community members; it contracts with the state Medicaid agency for waiver-funded supports and tailors the support plan to the individual. Originated in British Columbia in the 1980s and has spread unevenly across the U.S.; Tennessee, Louisiana, Virginia, and several Canadian provinces have established

microboard frameworks.

- **Intentional communities.** Faith-based and values-based residential communities organized around a shared way of life. *L'Arche* (founded 1964, now international) is the best-known: assistants and core members with intellectual disabilities live together as a household. *Camphill* communities, drawing on Rudolf Steiner's anthroposophy, operate roughly 100 communities across 20 countries, including a dozen in the United States. Other intentional-community models, including secular and other-faith variants, operate in various states.
- **Shared-living / host-home arrangements.** The beneficiary lives in the home of a non-related “host” family or individual who is contracted and trained as a Medicaid-funded support provider. Often the most home-like option for beneficiaries who do well in family settings but for whom the original family home is no longer available. Strongly favored under the HCBS Final Rule.
- **Supported-living agencies.** The beneficiary lives in their own apartment (rented in their own name or owned by a third-party SNT) with scheduled staff support from a Medicaid-contracted agency. Suits beneficiaries with greater independence and a smaller circle of needed supports.
- **Cooperative housing and co-located developments.** Several states have piloted co-housing developments specifically designed for adults with intellectual or developmental disabilities, with shared common space, on-site support staff, and individual or family-owned units. Availability is uneven; ask the state DD Council (Appendix A).

Funding for these models routes through the same HCBS waiver framework as traditional group homes; what changes is the setting and the support-delivery model, not the federal funding mechanism. The HCBS Final Rule (Part II) applies to all of them.

SELF-ADVOCATE VOICE

“I lived in a group home for three years and I asked to leave. Now I have my own apartment and a support worker who comes twice a day. The waiver pays the same money. The difference is I picked the place, and I picked the support worker, and that is what made it home.”

— An adult with autism, on housing choice

Vocational rehab funding, supplemental insurance, trustee succession check

- **Vocational rehab.** Re-engage your state DVR every few years; new technology, new programs, and changes in the beneficiary's capacity can open services that were not available at the initial age-18 evaluation.
- **Supplemental insurance.** Dental, vision, and supplemental medical coverage are gaps that Medicaid leaves; ABLE can fund them.
- **Trustee succession check (every 5 years).** Confirm the named trustee and at least two successors are still alive, competent, and willing. Brief each successor on the location of documents and current state of the Letter of Intent.

Parental death planning

~5 min read

This is the section parents put off the longest. Read it once and put it down. The point is not to dwell on the worst day. The point is to build the architecture that means the worst day does not also become the day the entire support system fails — so that whoever is in the room when the call comes can pick up a binder, follow the steps, and keep your child's life intact while they grieve.

The death of the second parent is the moment the entire architecture shifts from a parental responsibility to a trustee responsibility. The trust funding triggers, the Letter of Intent becomes the operating manual for whoever steps in, and a careful re-application of benefits is often required.

- **Trust funding triggers.** Second-to-die life insurance proceeds flow to the ILIT or directly to the SNT, depending on structure. Retirement-account beneficiary designations — if they correctly name the SNT — transfer as well.
- **Letter of Intent activation.** The current Letter of Intent, plus copies, should be in the hands of the successor trustee, the named guardian (if any), and at least one sibling or close family member.
- **Successor trustee briefing.** The successor trustee should already be familiar with the trust, the beneficiary, the attorney, and the tax professional. The death is not the moment for first introductions. Annual or bi-annual trustee-and-family meetings during the parents' lives prevent crisis-driven errors.
- **Benefit re-application timing.** Some benefits require notification of household composition changes; the trustee should know the timeline and reporting requirements. State HCBS waivers, in particular, typically require reporting of living-arrangement changes.
- **Sibling and extended-family roles.** Siblings often become informal advocates even when they are not named trustee. Clarify expectations in writing during the parents' lives — who will visit, who will attend IEP/IPP meetings, who will receive trust-distribution reports.

WHY THIS MATTERS

The Letter of Intent is the operating manual when you cannot be reached

Of every document in the special-needs planning binder, the Letter of Intent is the one most likely to be referenced daily by whoever steps in. The trust document is read by an attorney once a quarter. The Letter is consulted by a caregiver every day. Treat it accordingly: keep it current, keep copies in multiple hands, and review it on the same date every year.

A final word for parents in their 70s and 80s

Older parents often delay the harder conversations — succession, death planning, sibling expectations — because the conversations are emotionally difficult. The conversations do not get easier with time, and the cost of having them after a crisis (a stroke, a cancer diagnosis, a sudden death) is borne by the disabled adult child, who is the least equipped to absorb it. Schedule the meeting. Bring counsel. The kindest thing a parent can do for a special-needs adult child is to leave a clean, current, well-briefed architecture behind.

Sibling expectations — the conversation worth having early

Parents who have done estate planning for typical families often carry an assumption into special-needs planning that does not translate: that an inheritance will be split equally among the children, and that the non-disabled siblings will use their share to help the disabled sibling. Both halves of that assumption are load-bearing, and both are usually wrong in practice. A disabled adult on SSI and Medicaid *cannot* receive an outright inheritance without losing benefits; the share must route through a third-party SNT. The non-disabled siblings may want to help — but a written expectation that one sibling's inheritance will fund another sibling's care is a recipe for resentment, divorce-court exposure, and tax inefficiency.

Three structures handle this better than the implicit assumption:

- **Equalization through life insurance.** Parents buy a separate term or permanent policy naming the non-disabled sibling(s) directly. The SNT is funded through a different mechanism (second-to-die, retirement-account beneficiary designation). Each sibling receives a clear share through a clear instrument.
- **Charitable balance.** Some families fund the SNT generously and direct the residue of the estate to a charity meaningful to the family — community foundation, faith community, disability-advocacy nonprofit. The non-disabled siblings inherit nothing from the parents directly and are explicitly briefed on why; this is a values choice, made openly, not a surprise.
- **Trust-protector or co-trustee role for siblings.** Non-disabled siblings often want involvement without financial responsibility. A trust-protector or co-trustee role (with compensation) honors the relationship and uses the sibling's knowledge of the beneficiary without making the sibling personally liable for trust funds.

Whichever structure fits, the Letter of Intent is the place to set sibling expectations in writing. A sibling who reads in the LoI that Mom and Dad chose a corporate trustee precisely so the sibling would not have that burden — and that the sibling's role is to remain a brother or sister, not a fiduciary — receives that as a gift rather than a slight. The Sibling Leadership Network (siblingleadership.org) is a national peer organization for adult siblings of people with disabilities and is a useful resource for both the conversation and the years that follow it.

If you are the adult sibling — how to raise this with aging parents

This sub-section is written for a different reader: the adult brother or sister of someone with a disability, whose parents have not yet completed (or in some cases, started) this planning. The conversation is delicate. Parents who have spent decades caring for a disabled child often experience succession conversations as a question about their own mortality, or as a vote of no-confidence in their planning so far. Both are predictable; neither is what the sibling actually intends.

- **Lead with your own planning.** “I’m working on my own estate plan and the attorney asked who would step in for [sibling] if something happened to all of us. Can we talk through what you have in place?” The sibling becomes the one taking on a task, not the parents.
- **Ask about documents, not decisions.** “Do you have a Special Needs Trust drafted? Is there a Letter of Intent? Where is it kept?” You are asking for a map, not pushing a decision.
- **Offer a family meeting with counsel, not a unilateral plan.** “Would it help if we sat down with your attorney together — me, [other siblings], and you — so we all understand the structure?” The parents stay in charge; the siblings get briefed.

- **Name the cost of inaction without naming blame.** The most truthful sentence in this conversation is usually: “If something happened to both of you tomorrow, I would not know what to do next, and [sibling]'s life would change overnight. Help me know what to do.”
- **If the conversation stalls, offer to pay for the attorney consultation.** A grown child paying for the parents' SNT consultation is unusual but not unheard-of, and often breaks the inertia.

Most parents, once approached this way, are relieved rather than offended. They have been carrying the same fear; they did not know how to start. The Sibling Leadership Network and the Special Needs Alliance both publish peer accounts of how this conversation has gone in other families. Read one or two before the meeting.

PART V

Quick Reference

Federal limits, national resource directory, decision aids, glossary, and the companion online tools. State-specific directories appear in Appendix A and Appendix B at the back.

2026 federal limits table

Program / item	2026 amount	Source
SSI Federal Benefit Rate — individual	\$967/mo	SSA
SSI Federal Benefit Rate — couple	\$1,450/mo	SSA
SSI countable-resource limit — individual	\$2,000	SSA
SSI countable-resource limit — couple	\$3,000	SSA
SSI general income exclusion	\$20/mo	SSA
SSI earned income exclusion	\$65 + 50% of remainder	SSA
Substantial Gainful Activity — non-blind	\$1,620/mo	SSA
Substantial Gainful Activity — blind	\$2,700/mo	SSA
Trial Work Period — monthly threshold	\$1,160	SSA
ABLE annual contribution limit	\$19,000	IRC § 529A
ABLE-to-Work supplemental (1-person FPL)	Up to \$15,650	HHS poverty guideline
ABLE SSI safe-harbor	\$100,000	SSA POMS SI 01130.740
ABLE lifetime maximum	Set by each state plan; see Appendix A	Individual state plans
Federal gift-tax annual exclusion (per donee)	\$19,000	IRC § 2503
Federal estate-tax exclusion (lifetime)	\$13.99M (2026 indexed)	IRC § 2010
Medical expense deduction threshold (AGI)	7.5%	IRC § 213
State estate / inheritance taxes	Vary by state; consult state tax authority	State law

Source: Sources: SSA 2026 Cost-of-Living Adjustment notice; IRS 2026 inflation adjustments; HHS 2026 Poverty Guidelines; individual state ABLE program rules. Verify on respective agency websites at time of use — some 2026 thresholds released after publication may be indexed estimates here.

National resource directory

Resource	What it does	How to reach
The Arc of the United States	Largest national advocacy organization for people with intellectual and developmental disabilities. State and local chapters across the country.	thearc.org
Autism Society of America	Information, referral, advocacy, and chapter network.	autismsociety.org
National Down Syndrome Society (NDSS)	Advocacy, information, and policy work for individuals with Down syndrome and their families.	ndss.org
NAMI — National Alliance on Mental Illness	Education, support, and advocacy for individuals affected by mental illness; state and local affiliates.	nami.org
Easter Seals	Disability services for children and adults; therapy, employment, and community programs.	easterseals.com
United Cerebral Palsy	Services, advocacy, and resources for individuals with cerebral palsy and other disabilities.	ucp.org
Special Needs Alliance (SNA)	National professional association of attorneys focused on special-needs planning; maintains a public member directory by state. Listed for the reader's own research; not a recommendation of any individual member.	specialneedsalliance.org
National Academy of Elder Law Attorneys (NAELA)	National professional association of attorneys with elder-law and special-needs focus; state chapter directory and CELA (Certified Elder Law Attorney) credential program. Listed for the reader's own research; not a recommendation of any individual member.	naela.org
ABLE National Resource Center	Authoritative information on ABLE accounts; state-by-state plan comparison tool.	ablenrc.org
National Disability Rights Network	Federation of state protection-and-advocacy organizations — free legal advocacy for benefit denials and rights violations.	ndrn.org
Center for Parent Information and Resources	Hub for state Parent Training and Information centers (PTIs).	parentcenterhub.org

Resource	What it does	How to reach
Social Security Administration — Red Book	Authoritative work-incentives reference.	ssa.gov/redbook
U.S. Department of HUD — Section 811	Supportive housing for persons with disabilities.	hud.gov
Sibling Leadership Network	Resources and community for adult siblings of individuals with disabilities.	siblingleadership.org

STATE/LOCAL RESOURCE

Local chapters move faster than national offices

Most national organizations have state and county chapters. The local chapter is almost always a better first call than the national 800-number — same expertise, local knowledge of providers and waitlists, and shorter response times. Ask the national office for the local chapter contact, or search “[organization name] [your state or county].”

Decision tree — where does the money come from?

When a real expense comes up — a vacation, a dental appointment, a new wheelchair, a vocational program — the family has up to four potential funding sources. The decision sequence below is the default order in which to consider them. The decision should always be reviewed with the trustee and, for larger items, the special-needs attorney; this is a starting point, not a substitute.

Step	Question	If yes ...	If no ...
1	Is the expense covered by Medicaid, SSI, the state HCBS waiver, school IEP, or other public benefit?	Use the benefit. Document the request and denial trail if benefit is partial.	Continue to Step 2.
2	Is the expense a qualified disability expense for ABLE, and is the ABLE balance available?	Withdraw from ABLE (preferred for housing, transportation, education, basic living expenses; remember same-month housing rule).	Continue to Step 3.
3	Is the expense a permitted SNT distribution under the trust document, and would the distribution preserve SSI/Medicaid (not in-kind support)?	Trustee distributes from the SNT directly to the third-party vendor (not to the beneficiary). Document.	Continue to Step 4.
4	Are parents able and willing to pay out-of-pocket?	Parents pay directly; preserve receipts for medical-expense deduction if applicable.	Re-scope the expense, defer, or seek charitable / sliding-scale alternatives.

WHY THIS MATTERS

Pay vendors directly from the trust whenever possible

An SNT distribution paid directly to a vendor (the dentist, the vacation provider, the wheelchair company) is not counted as income to the beneficiary. An SNT distribution paid to the beneficiary, who then pays the vendor, is counted as income and can reduce SSI. The direct-pay rule is the single most consequential operational rule of SNT administration.

Glossary

ABLE account	Tax-advantaged savings account for individuals with disability onset before age 26 (rising to 46 in 2026). IRC § 529A.
Crummey notice	Written notice to ILIT beneficiaries of a parent's gift to the trust, enabling that gift to qualify for the annual gift-tax exclusion.
d4A trust	First-party Special Needs Trust authorized by 42 U.S.C. § 1396p(d)(4)(A); holds the beneficiary's own assets; Medicaid payback at death.
d4C trust	Pooled trust authorized by 42 U.S.C. § 1396p(d)(4)(C); administered by nonprofit; available to over-65 beneficiaries; Medicaid payback at death.
DAC	Disabled Adult Child — an adult disabled before age 22 who may qualify for SSDI on a parent's earnings record.
Guardianship / Conservatorship	Court-ordered legal authority to make decisions on behalf of an adult lacking capacity. Statutory names and structures vary by state; most states recognize full, limited, and supported variants.
HCBS waiver	Home- and Community-Based Services waiver under § 1915(c) of the Social Security Act; the principal mechanism by which states fund long-term services and supports for individuals with disabilities outside institutional settings.
IEP	Individualized Education Program; written plan for special-education services in K-12 under IDEA.
ILIT	Irrevocable Life Insurance Trust; trust owning a life insurance policy on the parents, removing the proceeds from the parents' estates.
ISM	In-Kind Support and Maintenance; SSI treatment of food and shelter provided to the beneficiary, which can reduce SSI.
Letter of Intent	Narrative document, not legally binding, describing the beneficiary's care, routines, preferences, and life context for future caregivers.
LTSS	Long-Term Services and Supports; Medicaid-funded services such as group homes, day programs, in-home aides.
PASS	Plan to Achieve Self-Support; SSI work-incentive that shelters income for an explicit work goal.
POMS	Program Operations Manual System; SSA's authoritative internal procedural manual, publicly available.
SGA	Substantial Gainful Activity; monthly earnings threshold above which SSDI eligibility ends (\$1,620 non-blind, \$2,700 blind in 2026).
SNT	Special Needs Trust; legal vehicle holding assets for a disabled beneficiary without those assets counting against means-tested benefits.
SSDI	Social Security Disability Insurance; insurance-based disability benefit funded by payroll taxes; carries Medicare.

SSI	Supplemental Security Income; means-tested cash benefit for aged, blind, or disabled individuals with very limited income and assets; carries Medicaid in most states.
Third-party SNT	Special Needs Trust funded with someone other than the beneficiary's money (typically parents or grandparents); no Medicaid payback at death.
WIPA	Work Incentives Planning and Assistance; SSA-funded benefits-counseling service for working SSI/SSDI beneficiaries.
504 plan	Written plan of school accommodations for a student with a disability under Section 504 of the Rehabilitation Act.

Companion online tools

Four web-based calculators sit alongside this reference at **baratelliinstitute.com**. Each is free to use; none requires registration. The calculators are designed to make this reference operational — to let a family run the actual numbers from their own situation, then bring the printout to the attorney and tax professional.

Tool	What it does	URL
SNT Funding Calculator	Runs the Part III funding math — supplemental need, life expectancy, inflation, return — to project required SNT corpus at second parental death and the corresponding life insurance face amount.	baratelliinstitute.com/snt-funding
ABLE vs SNT Layering Tool	Models how a given dollar amount of family contribution should be split between ABLE (annual limit) and the third-party SNT, accounting for the \$100,000 SSI safe-harbor and ABLE-to-Work supplemental.	baratelliinstitute.com/able-snt-layering
Medicaid Cliff Calculator	For a working SSI beneficiary, shows the effective marginal tax + benefit-reduction rate on the next dollar of earned income, including SSI reduction, ABLE-to-Work eligibility, and SGA proximity.	baratelliinstitute.com/medicaid-cliff
Medical Expense Deduction Estimator	Estimates whether the family's annual disability-related medical and therapeutic expenses will exceed the 7.5%-of-AGI threshold, with a checklist of commonly missed categories.	baratelliinstitute.com/medical-deduction

WHY THIS MATTERS

Run the numbers before the meeting, not during

Attorney and tax-professional time is expensive and meetings are short. A family that arrives with the four-tool printout in hand spends the meeting answering the right questions instead of waiting for the calculator. It is this reference's most direct contribution to the family's cash flow.

Appendix A — Health, Disability & Advocacy Agencies (50 states + DC)

Each row lists one U.S. state (or the District of Columbia) and five federally-mandated or state-administered public agencies that families navigating disability planning will routinely need to contact. Every state has each of these entities: a Medicaid agency; a developmental-disabilities agency; a federally-funded Protection & Advocacy (P&A) system under the DD Assistance and Bill of Rights Act; a state Council on Developmental Disabilities (DD Council) funded under the DD Act; and at least one University Center for Excellence in Developmental Disabilities (UCEDD) funded under the DD Act. Use this appendix together with Appendix B (education, employment, and coordination agencies). Confirm current contact details on each agency's website at time of use; agency names and URLs change. This reference lists public agencies only; it does not recommend specific lawyers, accountants, financial planners, trustees, or private firms.

State	State Medicaid Agency	State Developmental Disabilities Agency	State Protection & Advocacy System (P&A)	State Council on Developmental Disabilities (DD Council)	University Center for Excellence in DD (UCEDD)
Alabama	Alabama Medicaid Agency (medicaid.alabama.gov)	Dept. of Mental Health, Division of Developmental Disabilities (mh.alabama.gov)	Alabama Disabilities Advocacy Program (ADAP, adap.ua.edu)	Alabama Council for Developmental Disabilities (acdd.org)	Civitan-Sparks Clinics, UAB (uab.edu/medicine/sparks)
Alaska	Alaska Dept. of Health, Division of Medicaid (health.alaska.gov)	Senior & Disabilities Services, DD Section (health.alaska.gov/dsds)	Disability Law Center of Alaska (dlcak.org)	Governor's Council on Disabilities & Special Education (gcdse.alaska.gov)	Center for Human Development, UAA (uaa.alaska.edu/chd)
Arizona	AHCCCS (azahcccs.gov)	Division of Developmental Disabilities, DES/DDD (des.az.gov/ddd)	Arizona Center for Disability Law (azdisabilitylaw.org)	Arizona Developmental Disabilities Planning Council (addpc.az.gov)	Sonoran UCEDD, U. of Arizona (sonoranucedd.fcm.arizona.edu)
Arkansas	Arkansas DHS Medicaid (humanservices.arkansas.gov)	DHS Division of Developmental Disabilities Services (humanservices.arkansas.gov/ddd)	Disability Rights Arkansas (disabilityrightsar.org)	Governor's Council on Developmental Disabilities (gcd.arkansas.gov)	Partners for Inclusive Communities, UAMS (uofapartners.uams.edu)
California	Medi-Cal / DHCS (dhcs.ca.gov)	Dept. of Developmental Services — 21 Regional Centers (dds.ca.gov)	Disability Rights California (disabilityrightscal.org)	State Council on Developmental Disabilities (scdd.ca.gov)	UCEDDs: USC UCEDD (uscucedd.org), Tarjan Center UCLA (tarjancenter.org), MIND Institute UC Davis (health.ucdavis.edu/mindinstitute)
Colorado	Health First Colorado / HCPF (hcpf.colorado.gov)	Office of Community Living, HCPF (hcpf.colorado.gov/office-community-living)	Disability Law Colorado (disabilitylawco.org)	Colorado Developmental Disabilities Council (coddc.org)	JFK Partners, U. of Colorado (medschool.cuanschutz.edu/jfkpartners)

State	State Medicaid Agency	State Developmental Disabilities Agency	State Protection & Advocacy System (P&A)	State Council on Developmental Disabilities (DD Council)	University Center for Excellence in DD (UCEDD)
Connecticut	Dept. of Social Services (portal.ct.gov/dss)	Dept. of Developmental Services (portal.ct.gov/dd)	Disability Rights Connecticut (disrightsct.org)	Connecticut Council on Developmental Disabilities (portal.ct.gov/cdds)	UConn Center for Excellence in Developmental Disabilities (uconnucedd.org)
Delaware	Delaware Health and Social Services, DMMA (dhss.delaware.gov/dmma)	DHSS Division of Developmental Disabilities Services (dhss.delaware.gov/dddsd)	Disabilities Law Program, Community Legal Aid Society (declasi.org)	Delaware Developmental Disabilities Council (ddc.delaware.gov)	Center for Disabilities Studies, U. of Delaware (cds.udel.edu)
District of Columbia	DC Dept. of Health Care Finance (dhcf.dc.gov)	Dept. on Disability Services, DDA (dds.dc.gov)	University Legal Services (uls-dc.org)	DC Developmental Disabilities Council (ddc.dc.gov)	Georgetown UCEDD (gucchd.georgetown.edu)
Florida	Agency for Health Care Administration (ahca.myflorida.com)	Agency for Persons with Disabilities — iBudget waiver (apd.myflorida.com)	Disability Rights Florida (disabilityrightsflorida.org)	Florida Developmental Disabilities Council (fddc.org)	Mailman Center for Child Development, U. of Miami (umiamihealth.org/mailman); FCIC, USF (cic.usf.edu)
Georgia	Georgia Dept. of Community Health (dch.georgia.gov)	Dept. of Behavioral Health and Developmental Disabilities (dbhdd.georgia.gov)	Georgia Advocacy Office (thegao.org)	Georgia Council on Developmental Disabilities (gcdd.org)	Center for Leadership in Disability, Georgia State U. (cld.gsu.edu); IHDD, U. of Georgia (ihdd.uga.edu)
Hawaii	Hawaii Med-QUEST Division (medquest.hawaii.gov)	Dept. of Health, Developmental Disabilities Division (health.hawaii.gov/ddd)	Hawaii Disability Rights Center (hawaiidisabilityrights.org)	Hawaii State Council on Developmental Disabilities (health.hawaii.gov/hiddcouncil)	Center on Disability Studies, U. of Hawaii Manoa (cds.coe.hawaii.edu)
Idaho	Idaho Dept. of Health and Welfare, Medicaid (healthandwelfare.idaho.gov)	DHW Division of Family and Community Services, DD Services (healthandwelfare.idaho.gov)	DisAbility Rights Idaho (disabilityrightsidaho.org)	Idaho Council on Developmental Disabilities (icdd.idaho.gov)	Center on Disabilities and Human Development, U. of Idaho (cdhd.idaho.edu)
Illinois	Illinois Dept. of Healthcare and Family Services (hfs.illinois.gov)	DHS Division of Developmental Disabilities; PUNS list (dhs.state.il.us)	Equip for Equality (equipforequality.org)	Illinois Council on Developmental Disabilities (illinois.gov/icdd)	Institute on Disability and Human Development, UIC (ahs.uic.edu/disability-human-development)
Indiana	Indiana FSSA, Office of Medicaid Policy and Planning (in.gov/fssa/ompp)	Bureau of Disabilities Services within FSSA-DDRS (in.gov/fssa/ddrs)	Indiana Disability Rights (in.gov/idr)	Indiana Governor's Council for People with Disabilities (in.gov/gpcpd)	Indiana Institute on Disability and Community, Indiana U. (iic.indiana.edu); Riley Child Development Center, IU School of Medicine (medicine.iu.edu)
Iowa	Iowa Health and Human Services (hhs.iowa.gov)	HHS Mental Health and Disability Services Division (hhs.iowa.gov)	Disability Rights Iowa (disabilityrightsiaowa.org)	Iowa Developmental Disabilities Council (iaddcouncil.org)	Center for Disabilities and Development, U. of Iowa (uichildrens.org/cdd)

State	State Medicaid Agency	State Developmental Disabilities Agency	State Protection & Advocacy System (P&A)	State Council on Developmental Disabilities (DD Council)	University Center for Excellence in DD (UCEDD)
Kansas	KS Dept. of Health and Environment, KanCare (kancare.ks.gov)	KDADS Community Services and Programs, IDD (kdads.ks.gov)	Disability Rights Center of Kansas (drckansas.org)	Kansas Council on Developmental Disabilities (kcdd.org)	KU Center on Developmental Disabilities, U. of Kansas (kucdd.ku.edu)
Kentucky	KY Cabinet for Health and Family Services, Medicaid (chfs.ky.gov/dms)	Dept. for Behavioral Health, DID Services (dbhdid.ky.gov)	Kentucky Protection & Advocacy (kypa.net)	Kentucky Commonwealth Council on Developmental Disabilities (chfs.ky.gov/ccdd)	Human Development Institute, U. of Kentucky (hdi.uky.edu)
Louisiana	LA Dept. of Health, Medicaid (ldh.la.gov)	Office for Citizens with Developmental Disabilities (ldh.la.gov/ocdd)	Disability Rights Louisiana (disabilityrightsla.org)	Louisiana Developmental Disabilities Council (laddc.org)	Human Development Center, LSU Health (hdc.lsuhscc.edu)
Maine	MaineCare Services (maine.gov/dhhs/oms)	Office of Aging and Disability Services (maine.gov/dhhs/oads)	Disability Rights Maine (drme.org)	Maine Developmental Disabilities Council (maineddcc.org)	Center for Community Inclusion and Disability Studies, U. of Maine (ccids.umaine.edu)
Maryland	Maryland Medicaid (health.maryland.gov/mmcp)	Developmental Disabilities Administration (health.maryland.gov/dda)	Disability Rights Maryland (disabilityrightsmd.org)	Maryland Developmental Disabilities Council (md-council.org)	Kennedy Krieger Institute UCEDD (kennedykrieger.org); Hussman Center, U. of Maryland Baltimore County (hussmancenter.umbc.edu)
Massachusetts	MassHealth (mass.gov/masshealth)	Dept. of Developmental Services (mass.gov/orgs/department-of-developmental-services)	Disability Law Center (dlc-ma.org)	Massachusetts Developmental Disabilities Council (mass.gov/orgs/massachusetts-developmental-disabilities-council)	Institute for Community Inclusion, UMass Boston (communityinclusion.org); E.K. Shriver Center, UMass Chan (umassmed.edu/shriver)
Michigan	Michigan Dept. of Health and Human Services (michigan.gov/mdhhs)	MDHHS Behavioral Health and Developmental Disabilities Administration (michigan.gov/mdhhs)	Disability Rights Michigan (drmich.org)	Michigan Developmental Disabilities Council (michigan.gov/mdhhs)	Developmental Disabilities Institute, Wayne State U. (ddi.wayne.edu)
Minnesota	Minnesota Dept. of Human Services (mn.gov/dhs)	DHS Disability Services Division (mn.gov/dhs)	Minnesota Disability Law Center (mylegalaid.org)	Minnesota Governor's Council on Developmental Disabilities (mn.gov/mnddc)	Institute on Community Integration, U. of Minnesota (ici.umn.edu)
Mississippi	Mississippi Division of Medicaid (medicaid.ms.gov)	Dept. of Mental Health, Bureau of IDD Services (dmh.ms.gov)	Disability Rights Mississippi (drms.org)	Mississippi Council on Developmental Disabilities (mscdd.org)	Institute for Disability Studies, U. of Southern Mississippi (usm.edu/disability-studies)

State	State Medicaid Agency	State Developmental Disabilities Agency	State Protection & Advocacy System (P&A)	State Council on Developmental Disabilities (DD Council)	University Center for Excellence in DD (UCEDD)
Missouri	MO HealthNet (dss.mo.gov/mhd)	Dept. of Mental Health, Division of Developmental Disabilities (dmh.mo.gov/dev-disabilities)	Missouri Protection & Advocacy Services (moadvocacy.org)	Missouri Developmental Disabilities Council (moddcouncil.org)	UMKC Institute for Human Development (ihd.umkc.edu); Thompson Center, U. of Missouri (thompsoncenter.missouri.edu)
Montana	Montana DPHHS, Medicaid (dphhs.mt.gov)	DPHHS Developmental Services Division (dphhs.mt.gov/dsd)	Disability Rights Montana (disabilityrightsmt.org)	Montana Council on Developmental Disabilities (mtcdd.org)	Rural Institute for Inclusive Communities, U. of Montana (ruralinstitute.umt.edu)
Nebraska	Nebraska DHHS, Medicaid (dhhs.ne.gov)	DHHS Division of Developmental Disabilities (dhhs.ne.gov/Pages/Developmental-Disabilities.aspx)	Disability Rights Nebraska (disabilityrightsnebraska.org)	Nebraska Council on Developmental Disabilities (ncdd.nebraska.gov)	Munroe-Meyer Institute, UNMC (unmc.edu/mmi)
Nevada	Nevada Medicaid (dhcfp.nv.gov)	Aging and Disability Services Division (adsd.nv.gov)	Nevada Disability Advocacy & Law Center (ndalc.org)	Nevada Governor's Council on Developmental Disabilities (nevadaddcouncil.org)	Nevada Center for Excellence in Disabilities, UNR (unr.edu/nced)
New Hampshire	NH DHHS, Medicaid (dhhs.nh.gov)	DHHS Bureau of Developmental Services (dhhs.nh.gov)	Disability Rights Center NH (drcnh.org)	NH Council on Developmental Disabilities (nhddc.org)	Institute on Disability, U. of New Hampshire (iod.unh.edu)
New Jersey	NJ FamilyCare / DMAHS (nj.gov/humanservices/dmahs)	Division of Developmental Disabilities (nj.gov/humanservices/ddd)	Disability Rights New Jersey (drnj.org)	NJ Council on Developmental Disabilities (njcdd.org)	Boggs Center on Developmental Disabilities, Rutgers (rwjms.rutgers.edu/boggscenter)
New Mexico	Human Services Dept., Medical Assistance Division (hsd.state.nm.us)	Developmental Disabilities Supports Division, Dept. of Health (nmhealth.org/about/ddsd)	Disability Rights New Mexico (drnm.org)	NM Developmental Disabilities Council (nmddc.org)	Center for Development & Disability, U. of New Mexico (cdd.unm.edu)
New York	NY State Dept. of Health, Medicaid (health.ny.gov)	Office for People With Developmental Disabilities (opwdd.ny.gov)	Disability Rights New York (drny.org)	NY Developmental Disabilities Planning Council (ddpc.ny.gov)	Westchester Institute for Human Development (wihd.org); Strong Center, U. of Rochester (urmc.rochester.edu/strong-center); Rose F. Kennedy UCEDD, Einstein (einsteinmed.edu)
North Carolina	NC DHHS, Division of Health Benefits (medicaid.ncdhhs.gov)	DHHS Division of MH/DD/SAS (ncdhhs.gov)	Disability Rights NC (disabilityrightsn.org)	NC Council on Developmental Disabilities (nccdd.org)	Carolina Institute for Developmental Disabilities, UNC (cidd.unc.edu)

State	State Medicaid Agency	State Developmental Disabilities Agency	State Protection & Advocacy System (P&A)	State Council on Developmental Disabilities (DD Council)	University Center for Excellence in DD (UCEDD)
North Dakota	ND DHHS, Medical Services Division (hhs.nd.gov)	DHHS Developmental Disabilities Division (hhs.nd.gov)	Protection & Advocacy Project of ND (ndpanda.org)	ND Council on Developmental Disabilities (nd.gov/dhs/dd-council)	ND Center for Persons with Disabilities, Minot State U. (ndcpd.org)
Ohio	Ohio Dept. of Medicaid (medicaid.ohio.gov)	Ohio Dept. of Developmental Disabilities (dodd.ohio.gov)	Disability Rights Ohio (disabilityrightsohio.org)	Ohio Developmental Disabilities Council (ddc.ohio.gov)	Ohio State U. Nisonger Center (nisonger.osu.edu); UC UCEDD, U. of Cincinnati (cincinnatichildrens.org/ucedd)
Oklahoma	Oklahoma Health Care Authority / SoonerCare (oklahoma.gov/ohca)	OK DHS, Developmental Disabilities Services Division (oklahoma.gov/okdhs)	Oklahoma Disability Law Center (oklahomadisabilitylaw.org)	Oklahoma Developmental Disabilities Council (okddc.ok.gov)	OU Health Sciences Center, Center for Learning and Leadership (ouhsc.edu)
Oregon	Oregon Health Authority, Health Systems Division (oregon.gov/oha)	Office of Developmental Disabilities Services (oregon.gov/dhs/seniors-disabilities)	Disability Rights Oregon (droregon.org)	Oregon Council on Developmental Disabilities (ocdd.org)	OHSU Institute on Development and Disability (ohsu.edu/idd)
Pennsylvania	DHS Office of Medical Assistance (dhs.pa.gov)	Office of Developmental Programs; Office of Long-Term Living (dhs.pa.gov)	Disability Rights Pennsylvania (disabilityrightspa.org)	PA Developmental Disabilities Council (paddc.org)	Institute on Disabilities, Temple U. (disabilities.temple.edu)
Rhode Island	RI EOHHS, Medicaid (eohhs.ri.gov)	Dept. of BHDDH (bhddh.ri.gov)	Disability Rights Rhode Island (drri.org)	RI Developmental Disabilities Council (riddc.org)	Paul V. Sherlock Center on Disabilities, Rhode Island College (sherlockcenter.ric.edu)
South Carolina	SC Dept. of Health and Human Services (scdhhs.gov)	SC Dept. of Disabilities and Special Needs (ddsn.sc.gov)	Protection & Advocacy for People with Disabilities, Inc. (pandasc.org)	SC Developmental Disabilities Council (scddc.state.sc.us)	Center for Disability Resources, USC School of Medicine (uscm.med.sc.edu/cdr)
South Dakota	SD Dept. of Social Services, Medical Services (dss.sd.gov)	DHS Division of Developmental Disabilities (dhs.sd.gov/developmentaldisabilities)	Disability Rights South Dakota (drsdlaw.org)	SD Council on Developmental Disabilities (dhs.sd.gov/ddc)	Center for Disabilities, USD Sanford School of Medicine (usd.edu/cd)
Tennessee	TennCare (tn.gov/tenncare)	Dept. of Disability and Aging (tn.gov/dda)	Disability Rights Tennessee (disabilityrightstn.org)	Tennessee Council on Developmental Disabilities (tn.gov/cdd)	Boling Center for Developmental Disabilities, UTHSC (uthsc.edu/bcdd); Vanderbilt Kennedy Center UCEDD (vkc.vumc.org)

State	State Medicaid Agency	State Developmental Disabilities Agency	State Protection & Advocacy System (P&A)	State Council on Developmental Disabilities (DD Council)	University Center for Excellence in DD (UCEDD)
Texas	Texas HHSC, Medicaid (hhs.texas.gov)	HHSC Office of Aging and Disability Services; HCS/CLASS waivers (hhs.texas.gov)	Disability Rights Texas (disabilityrightstx.org)	Texas Council for Developmental Disabilities (tcdd.texas.gov)	Texas Center for Disability Studies, UT Austin (tcds.edb.utexas.edu); UCEDD at UT Health Houston; Center on Disability and Development, Texas A&M
Utah	Utah Dept. of Health and Human Services, Medicaid (medicaid.utah.gov)	Division of Services for People with Disabilities (dspd.utah.gov)	Disability Law Center (disabilitylawcenter.org)	Utah Developmental Disabilities Council (utddc.utah.gov)	Utah State U. Center for Persons with Disabilities (cpd.usu.edu)
Vermont	Dept. of Vermont Health Access (dvha.vermont.gov)	Dept. of Disabilities, Aging and Independent Living (dail.vermont.gov)	Disability Rights Vermont (disabilityrightsvt.org)	Vermont Developmental Disabilities Council (ddc.vermont.gov)	Center on Disability & Community Inclusion, U. of Vermont (uvm.edu/cess/cdci)
Virginia	Dept. of Medical Assistance Services (dmas.virginia.gov)	Dept. of Behavioral Health and Developmental Services (dbhds.virginia.gov)	disAbility Law Center of Virginia (dlcv.org)	Virginia Board for People with Disabilities (vaboard.org)	Partnership for People with Disabilities, VCU (partnership.vcu.edu)
Washington	Washington Health Care Authority, Apple Health (hca.wa.gov)	DSHS Developmental Disabilities Administration (dshs.wa.gov/dda)	Disability Rights Washington (disabilityrightswa.org)	Washington State Developmental Disabilities Council (ddc.wa.gov)	Center on Human Development and Disability, U. of Washington (depts.washington.edu/chdd)
West Virginia	WV Bureau for Medical Services (dhr.wv.gov)	Office of Developmental Disabilities Services (dhr.wv.gov)	Disability Rights of West Virginia (drofwv.org)	WV Developmental Disabilities Council (ddc.wv.gov)	WV U. Center for Excellence in Disabilities (cedwvu.org)
Wisconsin	Wisconsin DHS, Medicaid (dhs.wisconsin.gov)	DHS Bureau of Aging and Disability Resources (dhs.wisconsin.gov)	Disability Rights Wisconsin (disabilityrightswi.org)	Wisconsin Board for People with Developmental Disabilities (wi-bpdd.org)	Waisman Center, U. of Wisconsin–Madison (waisman.wisc.edu)
Wyoming	Wyoming Dept. of Health, Division of Healthcare Financing (health.wyo.gov)	DOH Behavioral Health Division, DD Section (health.wyo.gov)	Protection & Advocacy System, Inc. (Wyoming P&A, wypanda.com)	Wyoming Governor's Council on Developmental Disabilities (wyddcouncil.org)	Wyoming Institute for Disabilities, U. of Wyoming (uwyo.edu/wind)

Source: Compiled from [Medicaid.gov](https://medicaid.gov); each state's developmental-disabilities agency public-facing website; the National Disability Rights Network directory of state Protection & Advocacy systems (ndrn.org); the National Association of Councils on Developmental Disabilities directory of state DD Councils (nacdd.org); and the Association of University Centers on Disabilities UCEDD directory (aucd.org). Every state has a federally-mandated P&A, DD Council, and at least one UCEDD under the Developmental Disabilities Assistance and Bill of Rights Act. Verify each agency's current contact information on its website before relying. Inclusion of a public agency is not an endorsement of any private individual, attorney, accountant, financial planner, or firm.

Appendix B — Education, Employment & Coordination Agencies (50 states + DC)

Each row lists one U.S. state (or the District of Columbia) and five additional public agencies under federal statute: the state education agency (the IDEA Part B lead for ages 3–21); the IDEA Part C lead agency for Early Intervention (birth-to-3); the state Vocational Rehabilitation agency under the Rehabilitation Act; the state Long-Term Services & Supports / Aging office (state unit on aging designated under the Older Americans Act, which in many states also administers Medicaid LTSS); and the state ABLÉ plan under IRC §529A. A small number of states do not operate their own ABLÉ plan; residents in those states use a partner state's plan, which is noted in the cell rather than shown as an em-dash. This reference lists public agencies and state-administered plans only; it does not recommend specific lawyers, accountants, financial planners, trustees, or private firms.

State	State Education Agency / IDEA Part B Office	State IDEA Part C Lead Agency (Early Intervention)	State Vocational Rehabilitation Agency	State Long-Term Services & Supports / Aging Office	State ABLÉ Plan
Alabama	Alabama State Dept. of Education, Special Education Services (alabamaachievers.org)	Alabama's Early Intervention System (AEIS), Dept. of Rehabilitation Services (rehab.alabama.gov/aeis)	Alabama Dept. of Rehabilitation Services, Vocational Rehabilitation Service (rehab.alabama.gov)	Alabama Dept. of Senior Services (alabamaageline.gov)	Enable Savings Plan Alabama (NE-administered); state tax deduction for AL residents.
Alaska	Alaska Dept. of Education and Early Development, Special Education (education.alaska.gov)	Early Intervention/Infant Learning Program, Alaska DHSS (health.alaska.gov/dsds/eilp)	Alaska Div. of Vocational Rehabilitation (labor.alaska.gov/dvr)	Alaska Senior & Disabilities Services (health.alaska.gov/dsds)	No state-specific plan — Alaska residents commonly use Ohio STABLE or Nebraska Enable; no AK state income tax.
Arizona	Arizona Dept. of Education, Exceptional Student Services (azed.gov/specialeducation)	Arizona Early Intervention Program (AzEIP), DES (des.az.gov/azeip)	AZ Rehabilitation Services Administration (des.az.gov/rsa)	Arizona Dept. of Economic Security, Division of Aging and Adult Services (des.az.gov/daas)	AZ ABLÉ (azable.gov); state tax deduction available.
Arkansas	Arkansas Division of Elementary and Secondary Education, Special Education (dese.ade.arkansas.gov)	Arkansas First Connections, Dept. of Human Services (dhs.arkansas.gov/dds/first-connections)	AR Division of Workforce Services, Rehabilitation Services (ace.arkansas.gov/dws)	Arkansas DHS Division of Aging, Adult, and Behavioral Health Services (humanservices.arkansas.gov)	Arkansas ABLÉ (savewithable.com/ar); state tax deduction.
California	California Dept. of Education, Special Education Division (cde.ca.gov/sp/se)	Early Start Program, Dept. of Developmental Services (dds.ca.gov/services/early-start)	CA Dept. of Rehabilitation (dor.ca.gov)	California Dept. of Aging (aging.ca.gov)	CalABLE (calable.ca.gov); CA conforms federal tax-free treatment; no state deduction.
Colorado	Colorado Dept. of Education, Exceptional Student Services Unit (cde.state.co.us/cdesped)	Colorado Early Intervention, Dept. of Early Childhood (coloradoofficeofearlychildhood.com)	Division of Vocational Rehabilitation, CDLE (dvr.colorado.gov)	Colorado Dept. of Human Services, State Unit on Aging (cdhs.colorado.gov/sua)	Colorado ABLÉ (coloradoable.com); state tax deduction.
Connecticut	Connecticut State Dept. of Education, Bureau of Special Education (portal.ct.gov/sde)	Birth to Three System, Office of Early Childhood (birth23.org)	Bureau of Rehabilitation Services (portal.ct.gov/aging-and-disability)	CT Dept. of Aging and Disability Services (portal.ct.gov/aging-and-disability)	ABLE CT (ablect.com); no state tax deduction.

State	State Education Agency / IDEA Part B Office	State IDEA Part C Lead Agency (Early Intervention)	State Vocational Rehabilitation Agency	State Long-Term Services & Supports / Aging Office	State ABLE Plan
Delaware	Delaware Dept. of Education, Exceptional Children Resources (doe.k12.de.us)	Birth to Three Early Intervention, DHSS (dhss.delaware.gov/dms/epqc)	Delaware Div. of Vocational Rehabilitation (dvr.delawareworks.com)	Delaware Division of Services for Aging and Adults with Physical Disabilities (dhss.delaware.gov/dsaapd)	DEPENDABLE (savewithable.com/de); no state tax deduction.
District of Columbia	DC Office of the State Superintendent of Education, Division of Specialized Education (osse.dc.gov)	Strong Start DC Early Intervention Program, OSSE (osse.dc.gov)	DC Rehabilitation Services Administration (dds.dc.gov/rsa)	DC Dept. of Aging and Community Living (dacl.dc.gov)	DC ABLE (dcable.com); no DC tax deduction.
Florida	Florida Dept. of Education, Bureau of Exceptional Education and Student Services (fldoe.org/academics/exceptional-student-edu)	Florida Early Steps, Dept. of Health (floridahealth.gov/programs-and-services/childrens-health/early-steps)	FL Div. of Vocational Rehabilitation (rehabworks.org)	Florida Dept. of Elder Affairs (elderaffairs.org)	ABLE United (ableunited.com); no FL state income tax.
Georgia	Georgia Dept. of Education, Division for Special Education Services and Supports (gadoe.org)	Babies Can't Wait, Dept. of Public Health (dph.georgia.gov/babiescantwait)	Georgia Vocational Rehabilitation Agency (gvs.georgia.gov)	Georgia Division of Aging Services (aging.georgia.gov)	Georgia STABLE (georgiastable.com); state tax deduction.
Hawaii	Hawaii Dept. of Education, Special Education (hawaiipublicschools.org)	Early Intervention Section, Dept. of Health (health.hawaii.gov/eis)	Hawaii Div. of Vocational Rehabilitation (humanservices.hawaii.gov/dvr)	Hawaii Executive Office on Aging (health.hawaii.gov/eoa)	No state-specific plan — Hawaii residents use Ohio STABLE partner; no state tax deduction.
Idaho	Idaho State Dept. of Education, Special Education (sde.idaho.gov/sped)	Infant Toddler Program, Dept. of Health and Welfare (healthandwelfare.idaho.gov)	ID Division of Vocational Rehabilitation (vr.idaho.gov)	Idaho Commission on Aging (aging.idaho.gov)	No state-specific plan — Idaho residents commonly use Ohio STABLE or Oregon ABLE; state tax-treatment varies, check Idaho State Tax Commission.
Illinois	Illinois State Board of Education, Special Education Department (isbe.net)	Illinois Early Intervention, Dept. of Human Services (dhs.state.il.us/page.aspx?item=31889)	IL Div. of Rehabilitation Services (drs.illinois.gov)	Illinois Dept. on Aging (ilaging.illinois.gov)	Illinois ABLE (illinoisable.com); state tax deduction.
Indiana	Indiana Dept. of Education, Office of Special Education (in.gov/doe/students/special-education)	First Steps Early Intervention, FSSA (in.gov/fssa/firststeps)	Indiana Vocational Rehabilitation Services (in.gov/fssa/ddrs)	Indiana FSSA Division of Aging (in.gov/fssa/da)	INvestABLE Indiana (savewithable.com/in); state tax credit for contributions.
Iowa	Iowa Dept. of Education, Bureau of Learner Strategies and Supports (educate.iowa.gov)	Early ACCESS Iowa (Dept. of Education lead) (iafamilysupportnetwork.org/early-access)	Iowa Vocational Rehabilitation Services (workforce.iowa.gov/ivrs)	Iowa Dept. of Health and Human Services, Aging Services (hhs.iowa.gov)	IABLE (iable.gov); state tax deduction.

State	State Education Agency / IDEA Part B Office	State IDEA Part C Lead Agency (Early Intervention)	State Vocational Rehabilitation Agency	State Long-Term Services & Supports / Aging Office	State ABLE Plan
Kansas	Kansas State Dept. of Education, Special Education and Title Services (ksde.org)	Kansas Infant-Toddler Services (KDHE) (ksits.org)	KS Rehabilitation Services (dcf.ks.gov/services/rs)	Kansas Dept. for Aging and Disability Services (kdads.ks.gov)	No state-specific plan — Kansas residents use Ohio STABLE partner; state tax deduction available for in-state contributions to KS-recognized plan.
Kentucky	Kentucky Dept. of Education, Office of Special Education and Early Learning (education.ky.gov)	First Steps (KY Early Intervention System), Cabinet for Health and Family Services (chfs.ky.gov/agencies/dph/dmch/ecdb)	KY Office of Vocational Rehabilitation (kcc.ky.gov)	Kentucky Dept. for Aging and Independent Living (chfs.ky.gov/agencies/dail)	STABLE Kentucky (savewithable.com/ky); no state tax deduction.
Louisiana	Louisiana Dept. of Education, Office of Diverse Learner Supports (louisianabelieves.com)	EarlySteps, LA Dept. of Health (ldh.la.gov/index.cfm/subhome/19)	LA Rehabilitation Services (lrs.dss.louisiana.gov)	Louisiana Governor's Office of Elderly Affairs (goea.louisiana.gov)	Louisiana ABLE (louisianaable.org); state tax deduction.
Maine	Maine Dept. of Education, Office of Special Services and Inclusive Education (maine.gov/doe/learning/specialed)	Child Development Services, Maine DOE (maine.gov/doe/learning/cds)	ME Bureau of Rehabilitation Services (maine.gov/rehab)	Maine Office of Aging and Disability Services (maine.gov/dhhs/oads)	ABLE ME (maineable.com); no state tax deduction.
Maryland	Maryland State Dept. of Education, Division of Early Intervention and Special Education Services (marylandpublicschools.org)	Maryland Infants and Toddlers Program, MSDE (marylandpublicschools.org)	MD Division of Rehabilitation Services (dors.maryland.gov)	Maryland Dept. of Aging (aging.maryland.gov)	Maryland ABLE (marylandable.org); state tax deduction.
Massachusetts	Massachusetts Dept. of Elementary and Secondary Education, Office of Special Education Planning and Policy (doe.mass.edu/sped)	Early Intervention, Dept. of Public Health (mass.gov/early-intervention-services)	MA Rehabilitation Commission (mass.gov/orgs/massachusetts-rehabilitation-commission)	Massachusetts Executive Office of Elder Affairs (mass.gov/orgs/executive-office-of-elder-affairs)	Attainable Savings Plan (Fidelity-administered); no state tax deduction.
Michigan	Michigan Dept. of Education, Office of Special Education (michigan.gov/mde/services/special-education)	Early On Michigan, MDE (1800earlyon.org)	MI Rehabilitation Services / Bureau of Services for Blind Persons (michigan.gov/mrs)	Michigan Aging & Adult Services Agency (michigan.gov/osa)	MiABLE (miable.org); state tax deduction.
Minnesota	Minnesota Dept. of Education, Special Education Division (education.mn.gov)	Help Me Grow Minnesota, MDE (helpmegrowmn.org)	Minnesota Vocational Rehabilitation Services (mn.gov/deed/job-seekers/vocational-rehab)	Minnesota Board on Aging (mnaging.net)	Minnesota ABLE Plan (mnable.org); state tax credit / deduction.
Mississippi	Mississippi Dept. of Education, Office of Special Education (mdek12.org/ose)	First Steps Early Intervention, MS Dept. of Health (msdh.ms.gov/firststeps)	MS Dept. of Rehabilitation Services (mdrs.ms.gov)	Mississippi Division of Aging and Adult Services, DHS (mdhs.ms.gov/adults-seniors)	ABLE MS (ablems.com); no state tax deduction.

State	State Education Agency / IDEA Part B Office	State IDEA Part C Lead Agency (Early Intervention)	State Vocational Rehabilitation Agency	State Long-Term Services & Supports / Aging Office	State ABLE Plan
Missouri	Missouri Dept. of Elementary and Secondary Education, Office of Special Education (dese.mo.gov/special-education)	First Steps, DESE (dese.mo.gov/special-education/first-steps)	MO Vocational Rehabilitation (vr.dese.mo.gov)	Missouri Division of Senior and Disability Services, DHSS (health.mo.gov/seniors)	MO ABLE (moable.com); state tax deduction.
Montana	Montana Office of Public Instruction, Special Education Division (opi.mt.gov)	Part C Early Intervention, DPHHS Developmental Services Division (dphhs.mt.gov/dsd/partc)	MT Vocational Rehabilitation and Blind Services (dphhs.mt.gov/detd/vrbs)	Montana DPHHS Senior and Long Term Care Division (dphhs.mt.gov/sltc)	Achieve Montana — primary 529 plan (does not offer ABLE); Montana residents commonly use Ohio STABLE; state tax deduction available for ABLE contributions.
Nebraska	Nebraska Dept. of Education, Office of Special Education (education.ne.gov/sped)	Nebraska Early Development Network, NDE (edn.ne.gov)	Nebraska VR (vr.nebraska.gov)	Nebraska DHHS State Unit on Aging (dhhs.ne.gov/Pages/Aging.aspx)	Enable Savings Plan (enablesavings.com); state tax deduction.
Nevada	Nevada Dept. of Education, Office of Special Education (doe.nv.gov)	Nevada Early Intervention Services, DHHS (adsd.nv.gov)	Bureau of Vocational Rehabilitation (detr.nv.gov/Page/Vocational_Rehabilitation)	Nevada Aging and Disability Services Division (adsd.nv.gov)	ABLE Nevada (savewithable.com/nv); no NV state income tax.
New Hampshire	NH Dept. of Education, Bureau of Special Education (education.nh.gov)	NH Family-Centered Early Supports and Services, DHHS (dhhs.nh.gov)	NH Vocational Rehabilitation, Dept. of Education (education.nh.gov)	NH Bureau of Elderly and Adult Services, DHHS (dhhs.nh.gov)	STABLE NH (savewithable.com/nh); no NH state income tax.
New Jersey	NJ Dept. of Education, Office of Special Education (nj.gov/education/specialed)	NJ Early Intervention System, Dept. of Health (nj.gov/health/fhs/eis)	NJ Div. of Vocational Rehabilitation Services (nj.gov/labor/dvrs)	NJ Division of Aging Services, DHS (nj.gov/humanservices/doas)	NJ ABLE (njable.gov); no state tax deduction.
New Mexico	NM Public Education Department, Special Education Bureau (webnew.ped.state.nm.us)	Family Infant Toddler Program, NM Dept. of Health (nmhealth.org)	NM Div. of Vocational Rehabilitation (dvr.state.nm.us)	NM Aging and Long-Term Services Department (aging.nm.gov)	ABLE New Mexico (savewithable.com/nm); state tax deduction.
New York	NY State Education Dept., Office of Special Education (nysed.gov/special-education)	NY Early Intervention Program, Dept. of Health (health.ny.gov/community/infants_children/early_intervention)	NY ACCES-VR (acces.nysed.gov/vr)	NY State Office for the Aging (aging.ny.gov)	NY ABLE (mynyable.org); state tax deduction.
North Carolina	NC Dept. of Public Instruction, Exceptional Children Division (dpi.nc.gov/districts-schools/classroom-resources/exceptional-children)	NC Infant-Toddler Program, DHHS (beearly.nc.gov)	NC Div. of Vocational Rehabilitation Services (ncdhhs.gov/divisions/dvrs)	NC Division of Aging and Adult Services (ncdhhs.gov/divisions/daas)	NC ABLE (savewithable.com/nc); no state tax deduction.

State	State Education Agency / IDEA Part B Office	State IDEA Part C Lead Agency (Early Intervention)	State Vocational Rehabilitation Agency	State Long-Term Services & Supports / Aging Office	State ABLE Plan
North Dakota	ND Dept. of Public Instruction, Office of Special Education (nd.gov/dpi/educators/special-education)	ND Early Intervention/Part C, DHHS Developmental Disabilities (hhs.nd.gov)	ND Vocational Rehabilitation (nd.gov/dhs/dvr)	ND Aging Services Division, DHHS (hhs.nd.gov/adultsaging)	No state-specific plan — North Dakota residents commonly use Ohio STABLE; state tax deduction may apply per ND Tax Commissioner guidance.
Ohio	Ohio Dept. of Education and Workforce, Office for Exceptional Children (education.ohio.gov)	Help Me Grow Early Intervention, Ohio DODD (ohioearlyintervention.org)	Opportunities for Ohioans with Disabilities (ood.ohio.gov)	Ohio Dept. of Aging (aging.ohio.gov)	STABLE Account (stableaccount.com); state tax deduction (and the largest ABLE platform nationwide, serving residents of many states).
Oklahoma	Oklahoma State Dept. of Education, Special Education Services (sde.ok.gov)	SoonerStart Early Intervention, OK State Dept. of Health (oklahoma.gov/health/family-health/screening-and-special-services)	OK Dept. of Rehabilitation Services (oklahoma.gov/drs)	Oklahoma Human Services, Community Living, Aging and Protective Services (oklahoma.gov/okdhs)	Oklahoma STABLE (savewithable.com/ok); state tax deduction.
Oregon	Oregon Dept. of Education, Office of Enhancing Student Opportunities (oregon.gov/ode)	Early Intervention/Early Childhood Special Education, Oregon DOE (oregon.gov/ode/students-and-family)	Oregon Vocational Rehabilitation (oregon.gov/dhs/employment/vr)	Oregon Aging and People with Disabilities, DHS (oregon.gov/dhs/seniors-disabilities/apd)	Oregon ABLE Savings Plan (oregonablesavings.com); state tax credit.
Pennsylvania	PA Dept. of Education, Bureau of Special Education (education.pa.gov)	Early Intervention, Office of Child Development and Early Learning (education.pa.gov/early-learning)	PA Office of Vocational Rehabilitation (dli.pa.gov)	PA Dept. of Aging (aging.pa.gov)	PA ABLE (paable.gov); state tax deduction.
Rhode Island	RI Dept. of Education, Office of Student, Community and Academic Supports (ride.ri.gov)	Early Intervention, RI EOHHHS / Dept. of Human Services (eohhs.ri.gov)	RI Office of Rehabilitation Services (ors.ri.gov)	RI Office of Healthy Aging (oha.ri.gov)	RI ABLE (rhodeislandsable.com); no state tax deduction.
South Carolina	SC Dept. of Education, Office of Special Education Services (ed.sc.gov)	BabyNet Early Intervention, SC Dept. of Health and Human Services (scfirststeps.org/babynet)	SC Vocational Rehabilitation Department (scvrd.com)	SC Dept. on Aging (aging.sc.gov)	Palmetto ABLE Savings Program (savewithable.com/sc); state tax deduction.
South Dakota	SD Dept. of Education, Special Education Programs (doe.sd.gov/sped)	Birth to Three Connections, DOE (doe.sd.gov/sped/btt.aspx)	SD Div. of Rehabilitation Services (dhs.sd.gov/rehabservices)	SD Division of Long Term Services and Supports, DHS (dhs.sd.gov/ltss)	No state-specific plan — South Dakota residents commonly use Ohio STABLE; no SD state income tax.

State	State Education Agency / IDEA Part B Office	State IDEA Part C Lead Agency (Early Intervention)	State Vocational Rehabilitation Agency	State Long-Term Services & Supports / Aging Office	State ABLE Plan
Tennessee	Tennessee Dept. of Education, Division of Special Populations (tn.gov/education/student-support/special-education)	Tennessee Early Intervention System, Dept. of Intellectual and Developmental Disabilities (tn.gov/didd/tennessee-early-intervention-system)	TN Vocational Rehabilitation Services (tn.gov/humanservices/ds/vocational-rehabilitation)	Tennessee Commission on Aging and Disability (tn.gov/aging)	ABLE TN (abletn.gov); no TN state income tax on wages.
Texas	Texas Education Agency, Special Education Department (tea.texas.gov/academics/special-student-populations/special-education)	Early Childhood Intervention Services, Texas HHSC (hhs.texas.gov/services/disability/early-childhood-intervention-services)	Texas Workforce Commission Vocational Rehabilitation (twc.texas.gov/programs/vocational-rehabilitation)	Texas HHSC Office of Aging Services Coordination (hhs.texas.gov)	Texas ABLE (texasable.org); no TX state income tax.
Utah	Utah State Board of Education, Special Education Services (schools.utah.gov/specialeducation)	Baby Watch Early Intervention, Utah Dept. of Health and Human Services (utahbabywatch.org)	Utah State Office of Rehabilitation (jobs.utah.gov/usor)	Utah Division of Aging and Adult Services, DHHS (daas.utah.gov)	ABLE Utah (utahable.org); state tax credit available.
Vermont	Vermont Agency of Education, Student Support Services (education.vermont.gov)	Children Integrated Services Early Intervention, Dept. for Children and Families (dcf.vermont.gov/cdd/cis)	Vermont Div. of Vocational Rehabilitation (vocrehab.vermont.gov)	Vermont Dept. of Disabilities, Aging and Independent Living (dail.vermont.gov)	Vermont ABLE (vermontable.com); no state tax deduction.
Virginia	Virginia Dept. of Education, Office of Special Education and Student Services (doe.virginia.gov)	Infant & Toddler Connection of Virginia, DBHDS (infantva.org)	VA Dept. for Aging and Rehabilitative Services (vadars.org)	Virginia Dept. for Aging and Rehabilitative Services, Division for the Aging (vda.virginia.gov)	ABLEnow (able-now.com); state tax deduction (and a national platform).
Washington	WA Office of Superintendent of Public Instruction, Special Education (k12.wa.us/student-success/special-education)	Early Support for Infants and Toddlers (ESIT), DCYF (dcyf.wa.gov/services/child-development-support/esit)	WA Div. of Vocational Rehabilitation (dshs.wa.gov/dvr)	WA Aging and Long-Term Support Administration, DSHS (dshs.wa.gov/altsa)	Washington State ABLE Savings Plan (washingtonstateable.com); no WA state income tax.
West Virginia	WV Dept. of Education, Office of Special Education (wvde.us/special-education)	WV Birth to Three, DHHR (wvdhhr.org/birth23)	WV Div. of Rehabilitation Services (wvdrs.org)	WV Bureau of Senior Services (boss.wv.gov)	WVABLE (savewithable.com/wv); state tax deduction.
Wisconsin	Wisconsin Dept. of Public Instruction, Special Education Team (dpi.wi.gov/sped)	Wisconsin Birth to 3 Program, DHS (dhs.wisconsin.gov/birthto3)	WI Div. of Vocational Rehabilitation (dwd.wisconsin.gov/dvr)	Wisconsin Bureau of Aging and Disability Resources, DHS (dhs.wisconsin.gov)	No state-specific plan — Wisconsin residents commonly use Ohio STABLE or other out-of-state plans; state tax-treatment varies, check WI Dept. of Revenue.
Wyoming	Wyoming Dept. of Education, Special Programs Division (edu.wyoming.gov)	Wyoming Early Intervention/Education Program, DOH (health.wyo.gov)	WY Div. of Vocational Rehabilitation (dws.wyo.gov/dws-division/vocational-rehabilitation)	Wyoming Aging Division, Dept. of Health (health.wyo.gov/aging)	No state-specific plan — Wyoming residents commonly use Ohio STABLE; no WY state income tax.

Source: Compiled from each state principal education agency, IDEA Part C lead agency, vocational rehabilitation agency, state unit on aging, and ABLE plan public-facing websites; cross-referenced with the U.S. Dept. of Education IDEA Data Center, the Administration for Community Living state agency directory, the Council of State Administrators of Vocational Rehabilitation (csavr.org), the National Association of Area Agencies on Aging (n4a.org), and the ABLE National Resource Center (ablenrc.org). Verify each agency current contact information on its website before relying. State tax treatment of ABLE contributions changes periodically; consult a tax practitioner licensed in your jurisdiction. Inclusion of a public agency or state-administered plan is not an endorsement of any private individual, attorney, accountant, financial planner, trustee, or firm.

Appendix C — Parent Training & Information Centers (PTI / CPRC) by state

Parent Training and Information Centers (PTIs) are federally funded under IDEA Part D (20 U.S.C. §§1471–1475). Every U.S. state and the District of Columbia has at least one PTI. PTIs provide free training, one-to-one assistance, IEP and §504 navigation, transition-planning support, and dispute-resolution coaching to parents of children with disabilities, birth through age 26. In addition, IDEA Part D funds Community Parent Resource Centers (CPRCs) in approximately thirty states; CPRCs serve parents in underserved communities (low-income, limited-English-proficient, parents with disabilities, geographically isolated). PTI and CPRC services are free to families. The Center for Parent Information and Resources (parentcenterhub.org) is the federally funded technical-assistance center that maintains the master directory and supports the parent-center network.

State	Parent Training & Information Center (PTI) — name & URL	Community Parent Resource Center (CPRC), if any — name & URL
Alabama	Alabama Parent Education Center (alabamaparentcenter.com)	—
Alaska	Stone Soup Group (stonesoupgroup.org)	—
Arizona	Raising Special Kids (raisingspecialkids.org)	Pilot Parents of Southern Arizona (pilotparents.org)
Arkansas	Arkansas Disability Coalition / PTI Project (adcpti.org)	FOCUS, Inc. (focusinc.org)
California	Matrix Parent Network & Resource Center (matrixparents.org); Disability Rights Education & Defense Fund PTI (dredf.org); Support for Families; Team of Advocates for Special Kids (taskca.org); Parents Helping Parents (php.com); Rowell Family Empowerment of N. California (rfenc.org); Family Resource Centers Network of CA (frcnca.org)	Loving Your Disabled Child (lydcla.org); Vietnamese Parent Resource Center; Fiesta Educativa (fiestaeducativa.org)
Colorado	PEAK Parent Center (peakparent.org)	El Grupo Vida (elgrupovida.org)
Connecticut	Connecticut Parent Advocacy Center, CPAC (cpacinc.org)	African Caribbean American Parents of Children with Disabilities, AFCAMP (afcamp.org)
Delaware	Parent Information Center of Delaware (picofdel.org)	—
District of Columbia	Advocates for Justice and Education, AJE (aje-dc.org)	—
Florida	Family Network on Disabilities (fndusa.org)	Parent to Parent of Miami (ptopmiami.org); Family Café (familycafe.net)
Georgia	Parent to Parent of Georgia (p2pga.org)	—
Hawaii	AWARE / Special Parent Information Network, SPIN (spinhawaii.org)	—
Idaho	Idaho Parents Unlimited (ipulidaho.org)	—
Illinois	Family Resource Center on Disabilities (frcd.org); Family Matters PTI (fmptic.org)	Designs for Change Chicago (designsforchange.org)

State	Parent Training & Information Center (PTI) — name & URL	Community Parent Resource Center (CPRC), if any — name & URL
Indiana	About Special Kids, ASK (aboutspeciallykids.org)	—
Iowa	ASK Resource Center (askresource.org)	—
Kansas	Families Together, Inc. (familiesaltogetherinc.org)	Keys for Networking (keys.org)
Kentucky	Kentucky Special Parent Involvement Network, KY-SPIN (kyspin.com)	—
Louisiana	Families Helping Families of Greater New Orleans (fhfogn.org); statewide FHF network (lafcl.org)	Project Prompt (familieshelpingfamilies.org)
Maine	Maine Parent Federation (mpf.org)	—
Maryland	Parents' Place of Maryland (ppmd.org)	—
Massachusetts	Federation for Children with Special Needs (fcsn.org)	Urban PRIDE (urbanpride.net)
Michigan	Michigan Alliance for Families (michiganallianceforfamilies.org)	Detroit Parent Network (detroitparentnetwork.org)
Minnesota	PACER Center (pacer.org)	—
Mississippi	Mississippi PTI, EMPOWER (msparentcenter.org)	Family Resource Center of North Mississippi (frcnms.org)
Missouri	Missouri Parents Act, MPACT (missouriparentsact.org)	—
Montana	Parents, Let's Unite for Kids, PLUK (pluk.org)	—
Nebraska	PTI Nebraska (pti-nebraska.org)	—
Nevada	Nevada PEP (nvpep.org)	—
New Hampshire	Parent Information Center of New Hampshire (parentinformationcenter.org)	—
New Jersey	Statewide Parent Advocacy Network, SPAN (spanadvocacy.org)	ASPIRE (Adelante en Servicios Para Inclusión, Recursos y Educación)
New Mexico	Parents Reaching Out (parentsreachingout.org)	EPICS — Education for Parents of Indian Children with Special Needs (epicsnm.org)
New York	Advocates for Children of New York (advocatesforchildren.org); INCLUDEnyc (includenyc.org); Parent to Parent of NYS (parenttoparentnys.org); Starbridge (starbridgeinc.org); Sinergia (sinergiany.org); Long Island Advocacy Center (liac.org)	United We Stand of NY (unitedwestandofny.org)
North Carolina	Exceptional Children's Assistance Center, ECAC (ecac-parentcenter.org)	Family Support Network of North Carolina (fsnnc.org)
North Dakota	Pathfinder Family Center (pathfinder.org)	Native American Family Network of ND (via Pathfinder)
Ohio	Ohio Coalition for the Education of Children with Disabilities, OCECD (ocecd.org)	Milestones Autism Resources (milestones.org)
Oklahoma	Oklahoma Parents Center (oklahomaparentscenter.org)	—

State	Parent Training & Information Center (PTI) — name & URL	Community Parent Resource Center (CPRC), if any — name & URL
Oregon	FACT Oregon (factoregon.org)	Oregon Family to Family Health Information Center (oregonfamilytofamily.org)
Pennsylvania	Parent Education and Advocacy Leadership Center, PEAL (pealcenter.org); Parent Education Network, PEN (parentednet.org); HUNE — Hispanos Unidos para Niños Excepcionales (huneinc.org); Mentor Parent Program (mentorparent.org)	HUNE — Latino CPRC (huneinc.org); ELECT (Pittsburgh)
Rhode Island	Rhode Island Parent Information Network, RIPIN (ripin.org)	—
South Carolina	Family Connection of South Carolina (familyconnectionsc.org); PRO-Parents of SC (proparents.org)	—
South Dakota	South Dakota Parent Connection (sdparent.org)	—
Tennessee	Support and Training for Exceptional Parents, STEP (tnstep.org)	—
Texas	Partners Resource Network — PATH, PEN, TEAM (partnerstx.org)	El Paso Parent Resource Center; Padres Unidos por la Educación Especial
Utah	Utah Parent Center (utahparentcenter.org)	—
Vermont	Vermont Family Network (vermontfamilynetwork.org)	—
Virginia	Parent Educational Advocacy Training Center, PEATC (peatc.org)	Formed Families Forward (formedfamiliesforward.org)
Washington	PAVE — Partnerships for Action, Voices for Empowerment (wapave.org); Open Doors for Multicultural Families (multiculturalfamilies.org)	Open Doors for Multicultural Families (multiculturalfamilies.org)
West Virginia	West Virginia Parent Training and Information, WV PTI (wvpti-inc.org)	—
Wisconsin	Wisconsin FACETS — Family Assistance Center for Education, Training and Support (wifacets.org)	—
Wyoming	Parent Information Center of Wyoming, PIC (wpic.org)	—

Source: Compiled from the Center for Parent Information and Resources (parentcenterhub.org), the federally funded technical-assistance center for the parent-center network under IDEA Part D. PTI and CPRC grantees are competitively re-awarded; verify the current grantee, contact details, and service area on parentcenterhub.org before relying. PTI and CPRC services are provided free of charge to families. Inclusion of a federally funded parent center is not an endorsement of any private individual or firm; this appendix lists public-mission organizations only.

Appendix D — Assistive Technology Act State Programs

Every U.S. state, the District of Columbia, and U.S. territories operate an Assistive Technology (AT) Act program funded under the Assistive Technology Act of 2004 (29 U.S.C. §§3001 et seq.). State AT Act programs are typically the fastest, lowest-cost path to getting hands on a communication device, a power wheelchair, a hearing or vision aid, a computer-access tool, or an environmental-control system — often *before* insurance or Medicaid authorization comes through. Core state-level services include: a short-term device-loan library (try before buying); device demonstration; training for individuals, family members, and professionals; equipment reuse and exchange programs (refurbished devices at low or no cost); and alternative-financing programs (low-interest loans for the purchase of AT). Services are available to people of any age and any disability. The Association of Assistive Technology Act Programs technical-assistance center (at3center.net) maintains the master directory.

State	Assistive Technology Act Program — name & URL	Services
Alabama	Alabama STAR (Statewide Technology Access & Response), Dept. of Rehabilitation Services (rehab.alabama.gov/star)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Alaska	Assistive Technology of Alaska, ATLA (atlaak.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Arizona	Arizona Technology Access Program, AzTAP, Northern Arizona U. (aztap.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Arkansas	Increasing Capabilities Access Network, ICAN (ar-ican.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
California	Ability Tools, CFILC (abilitytools.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Colorado	Assistive Technology Partners, U. of Colorado Anschutz (atpartners.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Connecticut	CT Tech Act Project, Dept. of Aging and Disability Services (cttechact.com)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Delaware	Delaware Assistive Technology Initiative, DATI, U. of Delaware (dati.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
District of Columbia	DC Assistive Technology Program, DCATP, University Legal Services (atpdc.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Florida	Florida Alliance for Assistive Services and Technology, FFAST (faast.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Georgia	Tools for Life, Georgia Tech / AMAC (gatfl.gatech.edu)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals

State	Assistive Technology Act Program — name & URL	Services
Hawaii	Assistive Technology Resource Centers of Hawaii, ATRC (atrc.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Idaho	Idaho Assistive Technology Project, IATP, U. of Idaho CDHD (idahoat.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Illinois	Illinois Assistive Technology Program, IATP (iltech.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Indiana	INDATA Project, Easterseals Crossroads (eastersealstech.com)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Iowa	Easterseals Iowa Assistive Technology Center (eastersealsia.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Kansas	Assistive Technology for Kansans, ATK, U. of Kansas (atk.ku.edu)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Kentucky	Kentucky Assistive Technology Service Network, KATS, Office of Vocational Rehabilitation (katsnet.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Louisiana	Louisiana Assistive Technology Access Network, LATAN (latan.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Maine	Maine CITE Coordinating Center (mainecite.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Maryland	Maryland Technology Assistance Program, MD TAP, Dept. of Disabilities (mdtap.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Massachusetts	MassMATCH, MA Rehabilitation Commission (massmatch.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Michigan	Michigan Assistive Technology Program, MATP, Michigan Disability Rights Coalition (mymdrc.org/matp)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Minnesota	STAR Program — System of Technology to Achieve Results, Dept. of Administration (mn.gov/admin/star)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Mississippi	Project START, Mississippi Dept. of Rehabilitation Services (mdrs.ms.gov/start)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Missouri	Missouri Assistive Technology, MoAT (at.mo.gov)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Montana	MonTECH, U. of Montana Rural Institute (montech.ruralinstitute.umt.edu)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals

State	Assistive Technology Act Program — name & URL	Services
Nebraska	Nebraska Assistive Technology Partnership, ATP, Dept. of Education VR (atp.nebraska.gov)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Nevada	Nevada Assistive Technology Resource Center, NATRC, Aging and Disability Services (adsd.nv.gov)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
New Hampshire	ATinNH, Institute on Disability, UNH (iod.unh.edu/projects/atinnh)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
New Jersey	Advancing Opportunities, NJ Statewide AT Advocacy and Awareness Program (advopps.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
New Mexico	New Mexico Technology Assistance Program, NMTAP, Division of Vocational Rehabilitation (nmtap.com)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
New York	TRAID — Technology Related Assistance for Individuals with Disabilities, Justice Center (justicecenter.ny.gov/traid)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
North Carolina	North Carolina Assistive Technology Program, NCATP, Division of Vocational Rehabilitation (ncdhhs.gov/divisions/dvrs/ncatp)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
North Dakota	North Dakota Assistive, NDA (ndassistive.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Ohio	Assistive Technology of Ohio, ATOhio, Ohio State U. (atohio.osu.edu)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Oklahoma	Oklahoma ABLE Tech, Oklahoma State U. (okabletech.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Oregon	Access Technologies, Inc., ATI (accesstechnologiesinc.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Pennsylvania	Pennsylvania Initiative on Assistive Technology, PIAT, Temple U. Institute on Disabilities (disabilities.temple.edu/piat)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Rhode Island	Assistive Technology Access Partnership, ATAP, Office of Rehabilitation Services (ors.ri.gov/atap)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
South Carolina	South Carolina Assistive Technology Program, SCATP, U. of South Carolina School of Medicine (scatp.med.sc.edu)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
South Dakota	DakotaLink, Black Hills Special Services Cooperative (dakotalink.net)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Tennessee	Tennessee Technology Access Program, TTAP, Council on Developmental Disabilities (tn.gov/cdd/programs/ttap)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals

State	Assistive Technology Act Program — name & URL	Services
Texas	Texas Technology Access Program, TxTAP, U. of Texas at Austin (txtap.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Utah	Utah Assistive Technology Program, UATP, Utah State U. Institute for Disability (uatpat.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Vermont	Vermont Assistive Technology Program, VATP, Division of Disability and Aging Services (vatp.vermont.gov)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Virginia	Virginia Assistive Technology System, VATS, Dept. for Aging and Rehabilitative Services (vats.dars.virginia.gov)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Washington	Washington Assistive Technology Act Program, WATAP, U. of Washington (watap.org)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
West Virginia	West Virginia Assistive Technology System, WVATS, WVU Center for Excellence in Disabilities (cedwvu.org/programs/wvats)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Wisconsin	WisTech, Dept. of Health Services (dhs.wisconsin.gov/disabilities/wistech)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals
Wyoming	Wyoming Assistive Technology Resources, WATR, U. of Wyoming WIND (uwo.edu/wind/watr)	Device-loan library; demonstration; training; reuse / exchange; alternative-financing referrals

Source: Compiled from the Association of Assistive Technology Act Programs technical-assistance center (at3center.net), the federally funded TA center for the State AT Act program network under 29 U.S.C. §§3001 et seq. State AT Act programs are competitively re-awarded; verify the current grantee, contact details, and current service offerings on at3center.net or the state program website before relying. Many state AT programs also operate alternative-financing programs offering low-interest loans for purchase of AT equipment — ask the state program for current loan-program details. Inclusion is not an endorsement of any private vendor or product.

Appendix E — Federal Statutory & Landmark Case Index

Reference index to the federal statutes and the U.S. Supreme Court decisions that structure the legal landscape this reference describes. Section A lists the principal statutes by short title and full Code citation. Section B lists the landmark cases by name, citation, and one-line holding, with a brief note on why the case matters to a family. Statutory text and judicial opinions are public-domain federal law; for application to a specific family situation, consult counsel licensed in your jurisdiction.

Section A — Key federal statutes

Statute (short title)	Citation	What it covers
Americans with Disabilities Act (ADA)	42 U.S.C. §§12101–12213	Comprehensive civil-rights statute prohibiting disability discrimination in employment (Title I), state and local government services (Title II), public accommodations (Title III), and telecommunications (Title IV).
Individuals with Disabilities Education Act (IDEA)	20 U.S.C. §§1400 et seq.	Federal special-education statute guaranteeing a free appropriate public education (FAPE) to children with disabilities ages birth through 21, structured around the IEP (Part B, ages 3–21) and the IFSP (Part C, birth–3).
Section 504 of the Rehabilitation Act	29 U.S.C. §794	Prohibits disability discrimination by any program receiving federal financial assistance; the source of school §504 plans and post-secondary accommodation rights.
Rehabilitation Act of 1973 (general)	29 U.S.C. §§701 et seq.	Authorizing statute for the state Vocational Rehabilitation system, the Client Assistance Program, and the Independent Living Services and Centers for Independent Living network.
Developmental Disabilities Assistance and Bill of Rights Act (DD Act)	42 U.S.C. §§15001 et seq.	Authorizing statute for the state Councils on Developmental Disabilities, the state Protection & Advocacy systems, the UCEDDs, and Projects of National Significance.
Stephen Beck Jr. ABLE Act	26 U.S.C. §529A	Tax-advantaged savings accounts for individuals with a qualifying disability with onset before age 26 (age 46 effective January 1, 2026 under the ABLE Age Adjustment Act); account balances under specified thresholds do not count toward SSI or Medicaid resource limits.

Statute (short title)	Citation	What it covers
Social Security Act — relevant disability titles	Title II SSDI (42 U.S.C. §§401 et seq.); Title XVI SSI (42 U.S.C. §§1381 et seq.); Title XVIII Medicare (42 U.S.C. §§1395 et seq.); Title XIX Medicaid (42 U.S.C. §§1396 et seq.)	The four federal income- and health-benefit programs structuring disability-benefit planning: SSDI, SSI, Medicare (24-month SSDI waiting period), and Medicaid (the long-term services and supports backbone).
Medicaid Special Needs Trust authority	42 U.S.C. §1396p(d)(4)(A) (first-party / individual self-settled SNT); §1396p(d)(4)(C) (pooled SNT)	The federal statutory authority permitting trusts holding the assets of an individual with a disability to be disregarded for Medicaid eligibility, subject to Medicaid-payback at death (d4A) or non-profit pooled administration (d4C).
§1915(c) HCBS waiver authority	42 U.S.C. §1396n(c)	Authorizes state Medicaid programs to waive certain institutional-eligibility requirements to fund home- and community-based long-term services and supports; the source of the state waiver waitlists discussed in Part II.
Older Americans Act (OAA)	42 U.S.C. §§3001 et seq.	Authorizing statute for the Administration for Community Living, the state units on aging, the Area Agencies on Aging, the Long-Term Care Ombudsman program, and aging-and-disability resource centers.
One Big Beautiful Bill Act (OBBBA, 2025)	Pub. L. No. 119-XX (2025); disability- and SNT-relevant provisions cross-reference 26 U.S.C. §529A and 42 U.S.C. §1396p as amended	2025 omnibus tax-and-spending legislation containing several special-needs-relevant provisions; readers should confirm the final enacted text and effective dates with the U.S. Government Publishing Office before relying.
Assistive Technology Act of 2004	29 U.S.C. §§3001 et seq.	Authorizing statute for the State AT Act Programs (see Appendix D), which provide device loan, demonstration, training, reuse, and financing services in every state.
Family Educational Rights and Privacy Act (FERPA)	20 U.S.C. §1232g	Federal law governing access to and confidentiality of student education records; controls who may obtain copies of IEPs, evaluations, and disciplinary records, and how parental access transfers at age of majority.
Health Insurance Portability and Accountability Act (HIPAA)	42 U.S.C. §§1320d et seq.; 45 C.F.R. Parts 160 and 164	Federal health-information privacy and security law; controls parental access to a child's medical records once the child reaches the age of majority absent a HIPAA release or guardianship/supported-decision-making authorization.

Section B — Landmark U.S. Supreme Court decisions

Case	Citation	Holding & why it matters
Olmstead v. L.C.	<i>527 U.S. 581 (1999)</i>	Holding: Unjustified institutional isolation of people with disabilities is discrimination under ADA Title II; states must provide community-based services when treatment professionals determine community placement is appropriate, the affected person does not oppose it, and placement can be reasonably accommodated. Why it matters: This is the legal backbone of the HCBS framework — the reason state Medicaid agencies must offer waiver-funded community services rather than defaulting to institutional placement.
Andrew F. v. Douglas County School District	<i>580 U.S. 386 (2017)</i>	Holding: An IEP must be reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances; the prior 'merely more than de minimis' floor is rejected. Why it matters: Raised the substantive standard for IDEA Part B FAPE compliance and gave parents stronger grounds to challenge an IEP that offers only trivial progress.
Smith v. Robinson + Handicapped Children's Protection Act of 1986	<i>468 U.S. 992 (1984); HCPA, Pub. L. 99-372 (1986)</i>	Holding (and legislative response): Smith held that IDEA was the exclusive remedy for special-education claims and barred attorney's-fee recovery; Congress responded with HCPA, which restored parental right to recover reasonable attorney's fees as prevailing parties in IDEA actions. Why it matters: Made due-process and federal-court IDEA litigation financially viable for many families.
Schaffer v. Weast	<i>546 U.S. 49 (2005)</i>	Holding: In an IDEA due-process hearing, the burden of persuasion rests on the party seeking relief (typically the parent challenging the IEP), absent a contrary state-law allocation. Why it matters: Parents must come to hearing prepared with evaluations, expert testimony, and a documented record; the school district does not bear the affirmative burden of proving the IEP is appropriate.
Honig v. Doe	<i>484 U.S. 305 (1988)</i>	Holding: IDEA's 'stay-put' provision prohibits school officials from unilaterally excluding a child with a disability from the classroom for misbehavior arising from the disability; suspensions of more than ten consecutive school days constitute a change in placement requiring procedural protections. Why it matters: Protects students from extended exclusionary discipline and forces districts to use manifestation-determination procedures.

Case	Citation	Holding & why it matters
Cedar Rapids Community School District v. Garret F.	<i>526 U.S. 66 (1999)</i>	Holding: Continuous one-on-one nursing services required for a student to attend school qualify as a 'related service' under IDEA, not as excluded 'medical services,' when they can be provided by a non-physician. Why it matters: Schools must provide the in-school nursing care needed for a medically complex student to participate in education, regardless of cost.
Sutton v. United Air Lines + ADA Amendments Act of 2008	<i>527 U.S. 471 (1999); ADAAA, Pub. L. 110-325 (2008)</i>	Holding (and legislative response): Sutton held that ADA disability determinations should consider mitigating measures (e.g., medication, prosthetics), narrowing coverage; the ADAAA legislatively reversed that approach and directed that mitigating measures (except ordinary eyeglasses and contact lenses) not be considered. Why it matters: ADA coverage is now broader; conditions controlled by medication or assistive devices still qualify as disabilities.
Tennessee v. Lane	<i>541 U.S. 509 (2004)</i>	Holding: ADA Title II validly abrogates state sovereign immunity as applied to cases implicating the fundamental right of access to the courts. Why it matters: People with disabilities can sue states for money damages when state failure to accommodate denies access to the judicial system.

Source: Statutory citations to the United States Code as published by the Office of the Law Revision Counsel of the U.S. House of Representatives (uscode.house.gov). Case citations to the United States Reports. Holdings stated for reference only; for application to a specific family situation, consult counsel licensed in your jurisdiction.

Appendix F — Title V Children & Youth with Special Health Care Needs (CYSHCN) State Programs

Every U.S. state and the District of Columbia operates a Title V Children and Youth with Special Health Care Needs (CYSHCN) program funded by the federal Title V Maternal and Child Health Services Block Grant administered by the HRSA Maternal and Child Health Bureau (mchb.hrsa.gov). State CYSHCN programs are the most under-recognized public resource in the special-needs family ecosystem: they provide *care coordination* for children with chronic and complex conditions, *family-to-family* peer support, *access to specialty care* (sometimes including direct payment for specialty consultation, diagnostic services, or treatment not otherwise covered), and assistance navigating the transition from pediatric to adult health care. Eligibility and the scope of direct services vary by state, but *care-coordination* services are typically open to any family with a child who has, or is at increased risk for, a chronic physical, developmental, behavioral, or emotional condition that requires health and related services of a type or amount beyond that required by children generally — regardless of income. Many families learn about Title V CYSHCN late in the journey; the recommendation is to ask the state CYSHCN program for an intake the same week the diagnosis is documented.

State	Title V CYSHCN Program — name & URL	Eligibility & services overview
Alabama	Children's Rehabilitation Service, CRS, Alabama Dept. of Rehabilitation Services (rehab.alabama.gov/crs)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Alaska	Health Services for Children with Special Needs, Section of Women's, Children's and Family Health, DPH (health.alaska.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Arizona	Office for Children with Special Health Care Needs, OCSHCN, Dept. of Health Services (azdhs.gov/prevention/womens-childrens-health/ocshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Arkansas	Children's Medical Services, CMS, Arkansas Dept. of Health (healthy.arkansas.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
California	California Children's Services, CCS, Dept. of Health Care Services (dhcs.ca.gov/services/ccs)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.

State	Title V CYSHCN Program — name & URL	Eligibility & services overview
Colorado	Health Care Program for Children with Special Needs, HCP, Dept. of Public Health and Environment (cdphe.colorado.gov/hcp)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Connecticut	Children and Youth with Special Health Care Needs Program, CYSHCN, Dept. of Public Health (portal.ct.gov/dph)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Delaware	Children with Special Health Care Needs Program, Division of Public Health (dhss.delaware.gov/dph/chca/dphcshcn.html)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
District of Columbia	Children and Youth with Special Health Care Needs Program, CYSHCN, DC Department of Health (dchealth.dc.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Florida	Children's Medical Services Managed Care Plan and Specialty Programs, CMS, Dept. of Health (cms-kids.com)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Georgia	Children's Medical Services, CMS, Dept. of Public Health (dph.georgia.gov/CMS)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Hawaii	Children with Special Health Needs Branch, CSHNB, Dept. of Health (health.hawaii.gov/cshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Idaho	Children's Special Health Program, CSHP, Dept. of Health and Welfare (healthandwelfare.idaho.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Illinois	Division of Specialized Care for Children, DSCC, U. of Illinois Chicago (dsccl.uic.edu)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.

State	Title V CYSHCN Program — name & URL	Eligibility & services overview
Indiana	Children's Special Health Care Services, CSHCS, Indiana Dept. of Health (in.gov/health/cshcs)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Iowa	Child Health Specialty Clinics, CHSC, U. of Iowa Stead Family Department of Pediatrics (chsciowa.org)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Kansas	Children & Youth with Special Health Care Needs Program, CYSHCN, Kansas Dept. of Health and Environment (kdhe.ks.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Kentucky	Office for Children with Special Health Care Needs, Cabinet for Health and Family Services (chfs.ky.gov/agencies/ccshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Louisiana	Children's Special Health Services, CSHS, LA Dept. of Health Office of Public Health (ldh.la.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Maine	Children with Special Health Needs Program, CSHN, Maine CDC (maine.gov/dhhs/mecdc/population-health/mch/cshn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Maryland	Children's Medical Services, CMS, Maryland Dept. of Health (health.maryland.gov/phpa/mch)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Massachusetts	Division for Children & Youth with Special Health Needs, DCYSHN, Dept. of Public Health (mass.gov/dcyshn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Michigan	Children's Special Health Care Services, CSHCS, Michigan Dept. of Health and Human Services (michigan.gov/mdhhs/cshcs)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.

State	Title V CYSHCN Program — name & URL	Eligibility & services overview
Minnesota	Children and Youth with Special Health Needs Program, MN CYSHN, Dept. of Health (health.state.mn.us/cyshn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Mississippi	Children's Medical Program, CMP, Mississippi State Dept. of Health (msdh.ms.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Missouri	Bureau of Special Health Care Needs, SHCN, Dept. of Health and Senior Services (health.mo.gov/living/families/shcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Montana	Children's Special Health Services, CSHS, Montana Dept. of Public Health and Human Services (dphhs.mt.gov/publichealth/cshs)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Nebraska	Children and Youth with Special Health Care Needs Program, Nebraska DHHS (dhhs.ne.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Nevada	Children with Special Health Care Needs Program, MCH, Nevada Division of Public and Behavioral Health (dpbh.nv.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
New Hampshire	Special Medical Services / Bureau of Family and Community Health, NH DHHS (dhhs.nh.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
New Jersey	Special Child Health Services, SCHS, Division of Family Health Services (nj.gov/health/fhs/sch)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
New Mexico	Children's Medical Services, CMS, New Mexico Dept. of Health Family Health Bureau (nmhealth.org)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.

State	Title V CYSHCN Program — name & URL	Eligibility & services overview
New York	Children and Youth with Special Health Care Needs Program, NYSDOH (health.ny.gov/community/infants_children/cshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
North Carolina	Children and Youth Branch, Women, Infants and Community Wellness Section, NCDHHS (ncdhhs.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
North Dakota	Children's Special Health Services, CSHS, ND Dept. of Health and Human Services (hhs.nd.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Ohio	Bureau for Children with Medical Handicaps, BCMH, Ohio Dept. of Health (odh.ohio.gov/bcmh)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Oklahoma	Family Support and Prevention Service / CSHCN, Oklahoma State Dept. of Health (oklahoma.gov/health/cshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Oregon	Oregon Center for Children and Youth with Special Health Needs, OCCYSHN, OHSU (occyshn.ohsu.edu)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Pennsylvania	Bureau of Family Health / Special Kids Network, SKN, Pennsylvania Dept. of Health (health.pa.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Rhode Island	Office of Children with Special Health Care Needs, RIDOH (health.ri.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
South Carolina	Children's Rehabilitative Services, CRS, SC Dept. of Health and Human Services (scdhhs.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.

State	Title V CYSHCN Program — name & URL	Eligibility & services overview
South Dakota	Children's Special Health Services, CSHS, SD Dept. of Health (doh.sd.gov/family/cshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Tennessee	Children's Special Services, CSS, Tennessee Dept. of Health (tn.gov/health/cfh/css)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Texas	Children with Special Health Care Needs Services Program, CSHCN, Texas Health and Human Services (hhs.texas.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Utah	Bureau of Children with Special Health Care Needs, CSHCN, Utah Dept. of Health and Human Services (cshcn.health.utah.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Vermont	Children with Special Health Needs Program, CSHN, Vermont Dept. of Health (healthvermont.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Virginia	Care Connection for Children, CCC, Virginia Dept. of Health (vdh.virginia.gov/care-connection-for-children)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Washington	Children with Special Health Care Needs Program, Washington State Dept. of Health (doh.wa.gov)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
West Virginia	Children with Special Health Care Needs Program, CSHCN, WV DHHR Bureau for Public Health (oeps.wv.gov/cshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.
Wisconsin	Children and Youth with Special Health Care Needs Program, CYSHCN, Wisconsin DHS (dhs.wisconsin.gov/cyshcn)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.

State	Title V CYSHCN Program — name & URL	Eligibility & services overview
Wyoming	Children's Special Health, CSH, Wyoming Dept. of Health (health.wyo.gov/publichealth/mch)	Care coordination open to any CYSHCN family regardless of income; direct-services and specialty-care payment programs are income-tested. Family-to-family support; transition-to-adult-care support; diagnostic and evaluation assistance.

Source: Compiled from the U.S. Health Resources and Services Administration Maternal and Child Health Bureau Title V Maternal and Child Health Services Block Grant program directory (mchb.hrsa.gov); the Association of Maternal and Child Health Programs state-program directory (amchp.org); and each state Title V agency public-facing website. State CYSHCN programs operate under different names (Children's Medical Services, Children's Special Health Care Services, Title V CYSHCN, and others) and re-organize periodically; verify the current program name, eligibility criteria, and intake process on the state agency website or mchb.hrsa.gov before relying. Inclusion is not an endorsement of any private clinical provider; the Title V CYSHCN program is the public-mission state agency, and care it funds is delivered through licensed providers selected by the family.

Finding professional advisors — a framework, not a directory

This reference does not recommend specific lawyers, accountants, financial planners, trustees, or firms. The right professional for a family depends on the state of residence, the complexity of the situation, the disability and life-stage of the beneficiary, and the subspecialty needed (special-needs trust drafting, SSI/SSDI appeals, guardianship/supported-decision-making, Medicaid waiver advocacy, trust taxation, benefit-aware financial planning). The framework below describes *what kind* of practitioner to look for, *what questions* to ask, and *where to research* credentials. The selection — and the responsibility for vetting — is the reader to make.

Legal counsel — what to look for

- **Licensed in good standing** in the state where the family resides and where the trust will be administered. State bar websites publish license-status look-ups.
- **Documented experience** drafting and administering first-party (d4A), third-party, and pooled (d4C) special-needs trusts; advising on SSI/Medicaid/HCBS-waiver interactions; and on the state guardianship / supported-decision-making continuum.
- **Engagement letter** that specifies the scope, the fee structure, and the willingness to coordinate with the family tax practitioner and financial planner.
- **Discovery paths.** National professional associations such as the Special Needs Alliance (specialneedsalliance.org) and the National Academy of Elder Law Attorneys (naela.org) maintain searchable member directories; the NAELA Certified Elder Law Attorney (CELA) credential is one peer-reviewed marker of focused practice. State bar associations operate lawyer-referral services. None of these is an endorsement; readers should interview multiple practitioners and confirm references before retaining.

Tax practitioner — what to look for

- **Active license** as a CPA, enrolled agent, or equivalent in the relevant jurisdiction, in good standing.
- **Demonstrated experience** with Form 1041 (grantor and non-grantor trust reporting), §1917(d)(4)(A) and (d)(4)(C) trust accounting, ABLE-account contribution coordination, the Saver Credit, and the medical-expense itemization rules under IRC §213.
- **Discovery paths.** State CPA societies maintain searchable member directories by practice area (trust and estate, elder care, special needs are common filters). The AICPA Personal Financial Planning Division lists members holding the Personal Financial Specialist (PFS) credential. The IRS maintains a searchable enrolled-agent directory. None of these is an endorsement; readers should interview multiple practitioners and confirm references before retaining.

Financial planner — what to look for

- **Fiduciary standard** in writing, applied to the entire engagement (not just the retirement account).
- **Demonstrated experience** coordinating trust assets with ABLE balances and benefit-eligibility rules; willingness to model second-to-die life insurance funding scenarios; and comfort with trust-as-beneficiary designations on retirement accounts.

- **Credential check.** CFP Board (cfp.net) publishes a verification look-up for CFP credential and disciplinary history. SEC adviser disclosure is available via adviserinfo.sec.gov; FINRA BrokerCheck (brokercheck.finra.org) covers registered representatives.
- **Compensation transparency.** The engagement letter should disclose every dollar of compensation — fee-only, commission, asset-based, or hybrid — in plain language. Walk away from anything else.

Questions to ask before retaining any of the three

- How many special-needs families have you worked with in the last five years?
- Have you drafted (or filed, or planned around) a §1917(d)(4)(A) or (d)(4)(C) trust in the last twelve months?
- What is your fee structure, in writing, including any third-party compensation?
- Will you coordinate directly with the two other members of the three-person team?
- Can you share references from special-needs families you have served?
- How are you licensed, by whom, and where can I verify your good standing?

Other Baratelli Institute resources

If this reference is useful, the family may find the following companion guides from The Baratelli Institute equally so. Each is designed in the same library-print standard and follows the same practitioner-grade, no-marketing approach.

Guide	What it covers	Best for
Estate Planning Decoded (EPD)	Comprehensive estate planning for families with complex assets — wills, revocable trusts, irrevocable trusts, ILITs, estate-tax planning, GST planning. New chapters on Special Needs Trust Architecture and Benefit Preservation Planning expand on this reference.	Parents building the broader estate plan around the SNT.
Family Office (FO) Reference	Operating model for families that have outgrown a single advisor — governance, investment policy, generational planning.	High-net-worth families coordinating SNT alongside broader wealth.
Trust Administration Guide	Practical mechanics of trust operation — trustee duties, accounting, distributions, beneficiary communication.	Successor trustees stepping into the SNT after parental death.
Athletes Wealth Playbook (AWP)	Wealth-management framework for professional athletes; includes family-formation planning and provisions for athletes raising children with special needs.	Athletes whose households include a child with disability.
Wealth Psychology Guide	The emotional architecture of financial decisions; useful for families navigating the long emotional arc of disability planning.	Any family finding the work of planning emotionally heavy.
The Baratelli Brief (newsletter)	Weekly practitioner-grade newsletter; subscription free.	Anyone who finds this reference useful and wants the ongoing thread.

Sources and citations

- Social Security Administration — 2026 Cost-of-Living Adjustment notice; 2026 SSI Federal Payment Amounts; SSA Red Book 2026 edition.
- 20 C.F.R. Part 404 (Social Security) and Part 416 (SSI), specifically §§ 404.1574, 416.1112.
- 42 U.S.C. § 1396p(d)(4)(A) and (d)(4)(C) (Special Needs Trust statutory authority).
- Section 1915(c) of the Social Security Act (Home- and Community-Based Services waivers).
- 26 U.S.C. §§ 213, 21, 25B, 529A, 2010, 2042, 2503 (medical expense deduction, dependent care credit, Saver Credit, ABLE, federal estate exclusion, ILIT estate inclusion, Crummey gifts).
- ABLE Age Adjustment Act, effective January 1, 2026, raising the disability-onset age threshold from 26 to 46.
- SSA Program Operations Manual System (POMS) sections SI 01120.203 (trusts), SI 01130.740 (ABLE accounts), SI 00835 (in-kind support and maintenance).
- IRS 2026 inflation adjustments — Revenue Procedure 2025 series; HHS 2026 Poverty Guidelines.
- Centers for Medicare & Medicaid Services HCBS Waiver program documentation; state-by-state § 1915(c) waiver inventories.
- Each state Medicaid agency, developmental-disability agency, state education agency, IDEA Part C lead agency, vocational rehabilitation agency, state unit on aging, and ABLE plan public-facing websites (compiled for Appendix A and Appendix B).
- National Disability Rights Network (ndrn.org), directory of state Protection & Advocacy systems federally mandated under the Developmental Disabilities Assistance and Bill of Rights Act.
- National Association of Councils on Developmental Disabilities (nacdd.org), directory of state DD Councils.
- Association of University Centers on Disabilities (aucd.org), directory of University Centers for Excellence in Developmental Disabilities (UCEDDs).
- U.S. Dept. of Education IDEA Data Center; Administration for Community Living state agency directory.
- Council of State Administrators of Vocational Rehabilitation (csavr.org); National Association of Area Agencies on Aging (n4a.org).
- ABLE National Resource Center FAQs and state-plan comparison tools (ablenrc.org).
- ERISA § 609(c) (disabled adult child health-coverage continuation).
- Special Needs Alliance position papers on third-party trust drafting (specialneedsalliance.org); listed as a public reference, not as a recommendation of any individual member.
- National Academy of Elder Law Attorneys (naela.org), Certified Elder Law Attorney (CELA) credential program; listed as a public reference, not as a recommendation of any individual member.
- AICPA Disability Planning Practice Guide (most recent edition); AICPA Personal Financial Planning Division.

Index of terms and statutory references

Alphabetical reference to the principal terms, statutes, programs, agencies, dollar limits, and concepts used in this reference. Page numbers refer to the page where the term is principally discussed; in cases where a term appears across several discussions, the primary page is listed first followed by secondary references.

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Page references are approximate and refer to the location of the principal discussion. Statutory citations are to U.S. federal law except where state law is noted; international readers should consult the translation note on page 3.

About the Author

The author is a CPA who has spent decades in operating and finance roles, including as a public-company CFO. The Baratelli Institute is the working notebook of that practice — patterns, frameworks, and references built from doing the work and shared with the next practitioner.

The Special Needs Family Financial Planning reference exists because families navigating diagnosis and benefit coordination deserve a single, accurate, public-agency-only reference — written from the practitioner discipline of doing the work, not the marketing discipline of selling it.

End of reference.

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