



Shield Special Needs Planning

Helping Families Plan for the Highest Quality of Life
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Four Pillars of Special Needs Planning

Special needs planning is an integrated system. Professional advisor coordination is key. If one pillar is missing, or siloed, families often end up in emergency mode.

Legal Structure: Protecting assets and loved ones with special needs.
(Wills, Trusts, Conservatorship/Alternatives, Trustees, Fiduciaries)

Public Benefits Strategy: Preserving SSI and Medi-Cal while positioning for DAC/CDB and Medicare/Medi-Cal dual eligibility.

Financial Design: Understanding and funding realistic care costs over a lifetime.
(insurance, savings, investments, creative fundraising, tax planning, accounting)

Lifestyle & Care Planning: Nurturing stability, independence, dignity,
competent caregiving, community integration—the highest quality of life.

What can happen to loved ones if you don't plan?

- Children can be left with nothing if you die while married with no will or trust.
- Who will care for your loved one with special needs? Do they know what to do, are they qualified? Can they communicate with your loved one?
- SSI and Medi-Cal can be lost because of income, assets, or other resources.
- Benefits can't cover everything; will your resources meet future needs?
- They may not access all the benefits they need, especially for medical care.
- Probate can drain your estate, robbing your loved one of much needed support.
- What will happen to your loved one if your assets are frozen for up to two years, because you only have a will and a power of attorney at death?
- How will future care givers provide the best care if you've left no instructions, videos, or clear guidance from a lifetime of learning?
- How will your loved one integrate into the community as fully as possible without supports, like a strong, person centered, Self-Determination Plan?

Pillar 1: Legal Structure

Most families use several core tools together. These are not interchangeable.

- **Will:** Nominate trusted guardians/conservators—you choose, not the state. Must coordinate with trust planning. A will alone goes through probate.
- **Parents' Revocable Living Trust:** Avoids probate, provides incapacity management, directs assets, and asset protection for beneficiaries. Valuable for parents and neurotypical children, not for special needs protection.
- **Standalone Third-Party Special Needs Trust (3P SNT):** Preferred 'asset warehouse.' Prevents SSI/Medi-Cal loss. No Medi-Cal payback. Others can gift, family can begin titling assets, practicing safe distributions, building accounting and tax filing structures—before passing away.
- **First-Party (Self-Settled) Special Needs Trust - 1P SNT / d(4)(A):** Used when money belongs to the beneficiary (settlement, direct inheritance). Prevents SSI/Medi-Cal loss. Requires Medi-Cal payback at death.
- **Pooled Special Needs Trust - d(4)(C):** Managed by a nonprofit with sub-accounts. Useful when no trustee is available or smaller estates. Prevents SSI/Medi-Cal loss. Medi-Cal/non-profit can claim/keep unspent funds.
- **CalABLE account:** A flexible tax-free savings and spending tool (especially for housing) that works alongside trusts, not instead of them. Helps prevent SSI/Medi-Cal loss.

Conservatorship/Powers of Attorney

At 18, parents lose automatic legal authority to make decisions for their child; if authority is still needed, a court petition is typically required.

Limited conservatorship of the person (7 powers):

- Decide where your loved one lives.
- Access confidential records (medical, educational, etc.).
- Enter into contracts.
- Consent to / refuse marriage.
- Consent to / refuse medical care (subject to legal limits and oversight).
- Control social/sexual relationships (courts are often reluctant).
- Make educational decisions.

Limited conservatorship of the estate: Manages and controls financial matters, collect benefits/income, pay bills, manage accounts, investments, and property.

Action plan: Courts are legally mandated to only grant the least restrictive powers needed to protect the person. Preparation is key to gaining the powers necessary to protect your loved one.

Conservatorship alternatives (when conservatorship is “too much”)

- **Advance Health Care Directive (medical/mental health):** if the person can understand.
- **Power of Attorney (financial/legal):** can be customized, but the person can typically revoke it.
- **Supported Decision-Making:** support team helps the person decide; but no legal authority to make final decisions.
- **Caution:** These alternatives require capacity to understand and can be changed/canceled by the signer; institutions may still demand formal authority for certain actions.

Testamentary SNT vs standalone 3rd Party SNT

A common mistake is relying on a parents' revocable living trust to create a 'special needs trust at death' (a testamentary SNT) as the main plan.

Testamentary SNT (created at death inside a will/living trust):

- The SNT does not exist during the parents' lifetime.
- Cannot be funded/receive gifts from family/friends while parents are alive.
- Cannot be designated as a beneficiary (life insurance/retirement)
- Possible benefit loss by direct distribution to beneficiary.
- Possible rejection by SSA because testamentary SNT can be revoked and/or grant authority to beneficiaries—assets can be countable and benefits lost.
- Easier to challenge, can become public record, greater uncertainty.

Standalone 3rd Party SNT (preferred for most families):

- Exists now and can be named immediately on gifts, trusts, life insurance.
- Allows grandparents and others to fund safely during lifetime or at death.
- Allows critical planning opportunities, like titling assets to the SNT, practicing proper income distribution, and ensuring accounting and tax filing structures are already in place, before parents die, rather than forcing the kind soul who has stepped up to care for your loved one to build the support structure.
- Benefits are protected if properly drafted and administered.
- Immediate asset protection against lawsuits, creditors, divorce, and other threats

Pillar 2: Public Benefits Strategy

Protecting SSI and Medi-Cal while planning for DAC/CDB and Medicare dual eligible transitions. Rules are complex, can change by age, specific disabilities, student or marital status, and other personal factors. This is a general overview.

Supplemental Security Income (2026)

- **Monthly benefit amount:** CA monthly maximum \$1233. This can add up to almost a million dollars over a lifetime!
- **Parental deeming:** ends at 18, parents' income and assets do not count.
- **Asset limit:** \$2,000 for an individual; \$3,000 for a couple.
- **Income Reductions:** unearned income = dollar for dollar reduction, earned income = one dollar reduction for every two dollars earned. After \$1253 (unearned) or \$2552 (earned) SSI drops to \$0. Possible redetermination after 12 months of excess income. Countable income can be reduced with deductions through IRWEs, PASS, SEIE, Employer Subsidies, and other ways.
- **SSI reductions common causes:** earnings, not paying rent, cash distribution, inheritance, child support, ISM, and other countable resources.

Medi-Cal (2026)

- **Full coverage:** Many ways to qualify through State/Federal programs.
- **Asset limits:** is \$130,000 for a one-person household; add \$65,000 for each additional household member (up to 10).
- **Monthly countable income limits:** unearned single/married \$1,677/\$2268; earned single/married \$3325/\$4508; above those limits, Medi-Cal may continue with a share of cost which can be very expensive.
- **Countable income:** a variety of formulas can reduce countable income substantially, often by more than half.
- **Medi-Cal payback:** At the beneficiary's death, the state can seek reimbursement for Medi-Cal benefits paid, up to the remaining balance of a first-party trust, pooled trust account or probate assets.
- **Payback protections:** 3rd Party SNT, Benefit Designation, or Family Trust.
- **Working Disabled Program (WDP):** Individuals with disabilities can work and keep full Medi-Cal, with income up to ~250% FPL (and often higher with exclusions). Income can exceed standard limits due to exclusions, often eliminating Share of Cost.
- **SSI linked Medi-Cal loss:** Often still eligible under state programs.

CalABLE accounts 2026

CalABLE is a tax-advantaged account for qualified disability expenses, including housing. It is a tool for spending flexibility - not a replacement for a trust.

- **Edibility age:** disability must occur before age 46 (up from 26).
- **Annual contribution limit:** \$19,000, with earned income up to \$35,650.
- **SSI protection threshold:** save up to \$100,000 with no SSI suspension.
- **CalABLE maximum account balance:** \$529,000.
- **Tax Free Savings and Withdrawals:** No taxes for interest earned or money withdrawn for qualified expenses
- **Benefits-safe spending:** Qualified ABLE withdrawals won't reduce SSI, and the ABLE balance is excluded for Medi-Cal eligibility.

DAC / CDB transition (Disabled Adult Child / Childhood Disability Benefits)

When a parent retires, becomes disabled, or dies, a disabled adult child may qualify for benefits on the parent's work record through Childhood Disability Benefits (CDB).

- Disability must have started before age 22 (and other eligibility rules apply).
- If the parent is living and retired/disabled, the benefit is generally up to about 50% of the parent's primary insurance amount (subject to family maximum).
- If the parent is deceased, the benefit is generally up to about 75%.
- Child benefit is in addition to parent benefit.
- SGA must be below \$1690 (non-blind) or \$2830 (blind) to qualify, but countable income can be reduced like SSI through IRWEs, PASS, and SEIE.

Automatic Medi-Cal (California) – DAC/CDB Dual Eligible Medi/Medi

- When the person with a disability qualifies for SSI, they are automatically eligible for Medi-Cal in California.
- When they transfer from SSI to DAC/CDB benefits in California, they keep Medi-Cal, and after 24 months are eligible for Medicare.
- Having both Medicare and Medi-Cal typically creates extremely strong coverage: Medi-Cal can act as a backup payer for things Medicare doesn't cover (such as premiums, deductibles, co-pays, IHSS, and long-term care services, depending on category and approvals).
- If private health insurance remains available due to disability eligibility rules, some families may effectively stack private insurance + Medicare + Medi-Cal.

Pillar 3: Financial Design

- Estimate monthly needs (housing, care, therapies, transportation, recreation).
- Project lifetime costs and inflation.
- Decide how to fund the gap: savings, investments, insurance, and coordinated gifts.
- Plan for trustee guidance, accountants, financial advisors, costs and oversight, not just 'family will handle it'.

Pillar 4: Lifestyle & Care Planning

The most critical pillar for your loved one's quality of life

- Letter of Intent: routines, preferences, medical history, behavioral supports, communication methods.
- Care team map: family, professionals, regional center resources, community supports.
- Housing plan: where and with whom the person will live as caregivers age.
- Successor decision-makers: trustees, advocates, and the practical 'how-to' for supporting the person well.

Plan for the highest quality of life

- **Protect the future, step by step:** Build stability through a sequence of small, coordinated protections — not one giant decision — by aligning legal documents, benefits rules, financial planning, and daily systems into one integrated structure. Consistent, manageable, step by step planning to get it done!
- **Build your circle of support:** Identify who will show up (family, successor caregiver, trusted friends, and professionals), clearly define roles and backups, nominate trusted successor trustees and agents, explore professional fiduciaries if necessary, and create both a contact tree and a practical "When Something Happens" guide for continuity.
- **Use the least-restrictive decision tools:** Start with supported decision-making, Advance Health Care Directives, and medical/financial powers of attorney; petition for limited conservatorship only when needed and narrowly tailored to ensure the greatest freedom and dignity, balanced with safety and appropriateness.

- **Protect benefits while growing resources:** Create a stand-alone third-party Special Needs Trust (SNT) now — even if unfunded — so gifts and inheritances have a safe, immediate destination; route family gifts correctly; coordinate an ABLE account as a flexible, beneficiary-owned spending tool that complements (not replaces) the trust.
- **Fund the plan efficiently and correctly:** Align life insurance, retirement accounts, brokerage accounts, and beneficiary designations to the SNT (or approved structure) so assets avoid probate and never land directly with your loved one in a way that disrupts SSI or Medi-Cal.
- **Make income predictable, not precarious:** Establish consistent wage-reporting routines; use representative payee or trustee-managed distributions when helpful; and structure support intentionally so housing and cash flow remain stable and benefits-safe.
- **Run clean administration:** Keep SNT, ABLE, and personal accounts separate; document spending carefully; maintain clear annual summaries; timely and accurate reporting to IRS/Social Security; and monitor/rebalance accounts to remain within SSI resource limits.
- **Plan healthcare for life:** Medi-Cal waivers for additional supports, ensure dual Medi-Cal/Medicare eligibility, timely filings for extended private insurance, keep provider lists, medications, authorizations, and protocols current in the Letter of Intent.
- **Create a home that endures:** Build the long-term housing vision, budget the supports (caregiving hours, transportation, adaptive technology, therapies, memberships), and coordinate ownership decisions to protect eligibility and long-term stability.
- **Use technology:** Implement autopay, refill and appointment reminders, medication supports, consent-based safety check-ins and monitoring, and identity-theft protections to reduce stress and prevent small mistakes from becoming crises. Use assist technologies for mobility, connection, community, and a fulfilling life.
- **Let excess income be a windfall not a disaster:** use expense letters, a first-person trust, and spend down strategies to convert "over the limit" cash into exempt assets or necessary supports — such as medical care, housing needs, adaptive equipment, debt payoff, all while protecting SSI and Medi-Cal.
- **Tell the story only you can tell:** Maintain a living Letter of Intent — and optionally a videos — capturing routines, communication style, comfort cues, behavioral supports, and care instructions so future caregivers can step in with clarity and confidence.

IMPORTANT ADVISORY: This handout is educational and not legal, tax, or benefits advice. Rules can vary by program category and individual facts. Confirm with a qualified specialist before acting.