

# Special Needs Planning: Fundamentals and Avoiding Common Pitfalls

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## What We Will Cover Today

- Review of special needs planning
- Summary of why public benefits are important
- Using Special Needs Trusts (SNT) to preserve eligibility and manage funds
- Knowing how to differentiate 1<sup>st</sup> and 3<sup>rd</sup> Party SNTs
- Staying informed about changes in special needs planning

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## What Does a Special Needs Planner Do?

Plans for the lifetime care of a person with a disability by:

- Aiding in accessing and preserving public benefits and resources
- Planning for financial support and management assistance
- Creating structure and guidance to sustain independence
- Informing about additional resources
- Protecting against creditors and predators
- Preserving assets for a person with a disability and heirs

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## What is a Special Needs Plan?

- Centered around planning for special needs individual's:
  - Financial needs;
  - Public benefit eligibility;
  - Healthcare and caregiving;
  - Advocacy;
  - Housing;
  - Work supports;
  - Education;
  - Hobbies and interests;
  - Social needs; and
  - Independence

Plan for future needs - Not  
just current needs

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## Any Clients?

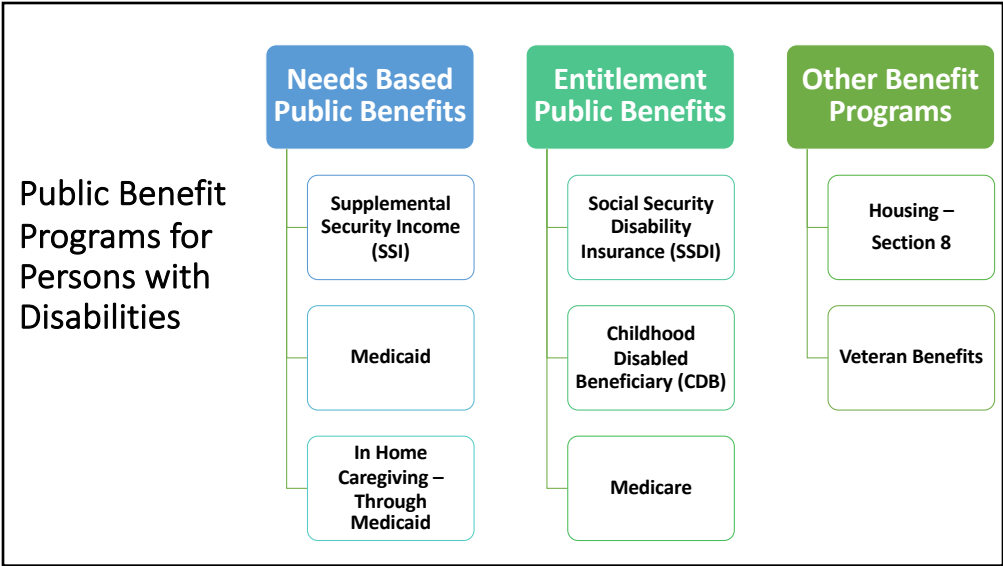
- About 56 million Americans -- one out of every five individuals -- has a disability
- 38 million Americans (1 in 10) live with a severe disability
- According to CMS, a 20-year old worker has a 1-in-4 chance of becoming disabled before reaching retirement age
- People with disabilities are the fastest-growing Medicare population group (about 16% of people on Medicare (9 million) are people with disabilities)
  - Learn more - <https://www.ssa.gov/disabilityfacts/>

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## Defining Disability

- Someone could be substantially disabled in the commonly understood sense (e.g., if the person must use a wheelchair for mobility), however, that individual would not be considered disabled under the SSI or Medicaid (in California Medicaid) rules if he or she holds a full-time job and earns a living wage
- “Disability” for public benefits is defined for an adult as the inability to engage in any “substantial gainful activity” (SGA) (for 2023 is \$1470/month) due to any medically determinable physical or mental impairment, or combination of impairments, that has lasted or can be expected to last for a continuous period of at least 12 months, or result in death

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Monthly Cash Benefit

SSI provides a monthly cash grant for food and shelter to disabled, blind, or the aged (65 or older)			
In 2023, the SSI federal maximum payment is \$914/month for an individual	Some States supplement this amount. (e.g., California provides a supplement)	Max SSI (2022) <b>\$1133</b> Individual	Presumed Maximum Value Penalty <b>\$324</b>

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## SSI Eligibility Requirements

- Disabled
- Income Test
  - Earned Income
  - Unearned Income
  - In Kind Support and Maintenance
  - Deemed Income
- Resource Test
  - Owning \$2,000 or more in assets will disqualify a person from SSI and categorically eligible Medicaid benefits
  - There are exempt assets. For example, one primary residence of any value and one car of any value, irrevocable pre-paid funeral contract
- If eligible for SSI, automatically eligible for full-scope Medicaid

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## Social Security Disability Insurance (SSDI)

### Basic Eligibility Criteria

- Disabled
- 40 SSA work credits, 20 of which must have been earned in the last 10 years
- Number of credits required is based on age, and when the individual becomes disabled.
- After Two Years – Qualify for Medicare
- At the beginning of 2019, Social Security paid an average monthly disability benefit of about \$1,234 to all disabled workers. That is barely enough to keep a beneficiary above the 2018 poverty level (\$12,140 annually).

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## Social Security – Childhood Disability Beneficiary

- The SSDI program pays benefits to adults whose disability began before the age of 22
- This program is currently called the Childhood Disability Beneficiary (CDB), formerly referred to as a Disabled Adult Child (DAC)
- The amount of the monthly check is roughly
  - 50 percent of the parent's monthly cash payment at retirement, and
  - 75 percent at death.

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## Public Benefits Confusion is Common



- Often people are confused about which public benefits are being received because:
  - Both SSI and SSDI are administered by the Social Security Administration (SSA) and checks come from the same place
  - Medicaid and Medicare are administered by the Centers for Medicaid and Medicare Services (CMS) and medical services are paid, but often difficult for consumers to know who paid
- Tips for knowing if SSI:
  - SSI arrives on the first of the month (note if dual-eligible on the 3<sup>rd</sup> of the month)
  - Check whether the amount exceeds SSI maximums (*e.g.* in 2023 is \$914 for an individual)

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**Disability Benefits 101**  
working with a disability

Disability Benefits 101 gives you tools and information on employment, health coverage, and benefits. You can plan ahead and learn how work and benefits go together.

**Where to Find Help**  
<https://www.db101.org>

**Alaska**  
☐ Always go to Alaska

**Arizona**  
☐ Always go to Arizona

**California**  
☐ Always go to California

**Michigan**  
☐ Always go to Michigan

**Minnesota**  
☐ Always go to Minnesota

**Missouri**  
☐ Always go to Missouri

**New Jersey**  
☐ Always go to New Jersey

**Ohio**  
☐ Always go to Ohio



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## The Special Needs Trust

- The Special Needs Trust is the primary planning tool to plan for persons with disabilities
- Special Needs Trusts
  - Different types depend on whose money is being used to fund the trust
  - No requirement that trust be called a "special needs trust"

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## Different Types of Planning for 1<sup>st</sup> and 3<sup>rd</sup> Party Funds

- First party planning (planning for the person with a disability own assets)
  - (d)(4)(A) SNT (aka, a “Payback SNT”)
  - (d)(4)(C) SNT (aka, a “Pooled SNT”)
  - ABLE Account
- Third party planning (planning for the person with assets owned by any other third party, *e.g.*, parent, other relative, or donations from third parties (crowd funding)
  - Third Party SNT
  - Pooled SNT
  - ABLE Account

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## Common First-Party Planning Scenarios

Person with a disability receives a litigation recovery

Person with a disability receives an inheritance, windfall, or gift with no advance planning

Person becomes disabled later in life after acquiring assets, *e.g.*, some schizophrenics’ break with reality occurs in their late 20s or early 30s

Child support payments – considered child’s income for public benefit purposes

Soon-to-be ex-spouse with disabilities who could not qualify for SSI during the marriage due to deeming

UTMA accounts

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## Common Third Party SNT Scenarios

Called a third party SNT because it is established with the assets of someone other than a person with a disability

Most common is the Third Party Special Needs Trust for a parents/grandparents' inheritance for a loved one with a disability

Can be any third-party who directs assets into the third party SNT, *e.g.*, crowdfunding

May be called a “Supplemental Needs Trust” or “Special Need Trust” – no difference

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## Be Wary – Not Always Easy to Distinguish Funding

- Oftentimes clients look for ways to treat the trust as Third Party SNT because there is no payback to the government on death and less restrictive rules in the administration
  - May think that direct distribution of a person with a disability's inheritance to a third party SNT is authorized, but it's not
- Need to check the terms of SNT document to see if meets First Party SNT or Third Party SNT legal requirements

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## First Party Special Needs Trust

Set up by individual, parent, grandparent, legal guardian or a Court

To or for the sole benefit of a person who is disabled and under age 65

Funded with the assets of the person who is disabled

Payback required to reimburse the State for Medicaid Paid

- 42 U.S.C. § 1396p (d)(4)(A)

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## Third Party Special Needs Trusts

Trust created by trustor (*e.g.* parent) for the benefit of person other than the grantor (*e.g.* loved one w/special needs)

- Can be created during lifetime of the grantor or at death (testamentary – as part of Will or trust)
- Can be revocable or irrevocable during the lifetime of the trustor

If revocable, the third party trust would be taxed as a grantor trust under IRC § 676

- This occurs when 3<sup>rd</sup> Party SNT set up during parents' lifetime and they have right to revoke
- Taxed as "grantor" trust to parents

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## Improper Third-Party Planning

- Limited one-dimensional third-party planning
  - Focused only on preserving public benefits
  - Advocacy and care giving
  - Multiple beneficiaries
  - Coordination with family members
  - Memorandum of Intent
- Drafting third party SNTs to include First Party SNT requirements
  - No payback required
  - No sole benefit required

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## Other Planning Arrangements Not Recommended

- **Outright inheritance** – loss of SSI and Medicaid
- **Left in non-qualifying trust** – loss of SSI and Medicaid
- **Disinheritance** – no money legally available for child with a disability
- **Leaving assets to siblings** with request to take care of sibling with disability – Not wise
  - ▶ Subject to their creditors
  - ▶ What if they die who then has assets
  - ▶ May not want to take care of brother/sister if have own family
  - ▶ Could be lost in divorce

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## Properly Planning for the Management Team

- Too often, the plan is to let siblings or other family members manage the lifetime care of a person with disability
- Oftentimes, parents have not asked siblings their thoughts, or even if they say yes:
  - What happens if they have their own family
  - What happens if they move across the country
  - What happens if they do not get along with their siblings after their parents die?
- Even with an SNT, planning sometimes forgets who will make decisions for person with a disability without the capacity to manage their own affairs and needs a court-appointed Conservator or Agent

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## The Ideal SNT Trustee

Understands all laws (and changes to laws) necessary to manage a trust	Understands all laws (and changes to laws) to keep and maintain public benefits	Always acts in the best interest of beneficiary – no self-dealing or favoring others	Expertise in investing funds for person with a disability
Makes tax efficient decisions for income, property, employment, etc.	Keeps impeccable books and records	Carries insurance, is bondable and has deep pockets	Can identify and rectify abuse, discrimination, or second-rate service
Knowledgeable on all aspects of owning real estate	Employs excellent care managers and caregivers and follows all employment laws	Excellent communicator is firm but kind but able to say No if necessary	Is psychic, immortal and omniscient

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## My Gold Standard SNT Management Team

- **Professional Trustee** – private professional fiduciary/corporate fiduciary experienced in SNT administration
  - Manages day-to-day administrative duties, all investment authority, full discretionary authority, all typical trustee fiduciary duties
- **Trust Advisory Committee** – family members/friends
  - Right to advise on distributions, but not control
  - Remove and replace Trustee with or without cause
  - Right to access all trust records and accountings
- **Trust Protector** – either family member/friend or right to appoint by TAC
  - Right to amend trust agreement if change in public benefit laws or for administrative purposes
- **Care Manager and Advocate**
  - Designed to instruct Trustee and TAC when to hire needed professionals



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## Use a Memorandum of Intent

- In third party planning, the most critical document for customized plans
  - Add in specifics of a person with a disability
  - Keep updated (reminder to do it on the person's birthday)
- Prepare trust provision to have SNT Management Team review and utilize when interpreting "intent"

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## What is a Memorandum of Intent?

- Lays out Settlor's goals and expectations:
  - Details loved ones and Settlor's preferences, needs, wishes, both medical and personal
  - Lists key people in child's life
- Settlor's experiences and what Settlor has learned is available and becomes a key resource for:
  - Family members
  - Trustees
  - Caregivers
  - Attorneys and the Court
  - Medical professionals
  - Many others
- Not legally binding, but will be reviewed and to the maximum extent allowed, followed



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## Significance of the Memorandum of Intent

- In third party planning, most critical document for customized plans
  - Drafting specific distributions into legally binding trust often does not make much sense, but much better suited for Memo of Intent
  - Add in specifics of person with disability
  - Keep updated (reminder to do it on person's birthday)
- Prepare trust provision to have SNT Management Team review and utilize when interpreting "intent"
- At a minimum, send Memorandum of Intent guidelines to client and link to Workshop on Creating Memo of Intent

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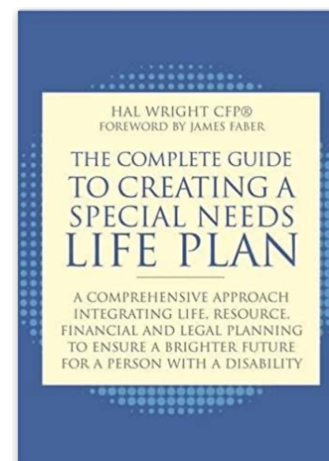
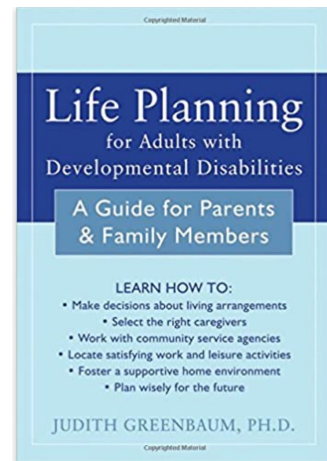
## Complimentary Parent Workshop on Creating a Memorandum of Intent for Loved One with Special Needs

[www.MovingtoMastery.com](http://www.MovingtoMastery.com)

[www.movingtomastery.com/courses/2021-parent-workshop-creating-your-memorandum-of-intent-for-a-loved-one-with-special-needs](http://www.movingtomastery.com/courses/2021-parent-workshop-creating-your-memorandum-of-intent-for-a-loved-one-with-special-needs)



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## Obtaining Proper Investment and Funding Advice

- Too often financial planning is inadequate, or once the attorney finishes drafting the third-party SNT, the parents ask “how much money should we fund our trust to protect our child”
- Autism Speaks estimates that the lifetime cost for an individual with autism or intellectual disability averages \$1.4 - \$2.4 million
- For many families, the net assets for a child with a disability are insufficient, so it is important to consider permanent insurance (not term - except as a short time solution)

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## Budgeting & Forecasting

### Target Spending Plan or Budget

- Determine “wish list” of needs/wants
- Collaboration with expert professionals
- Alternative Solutions (Placement)
- Prioritization

### Testing the Spending Plan or Budget

- Age, Life Expectancy: **RATED AGE & Actuarial Life Expectancy**
- Inflation
- Taxation
- Risk Tolerance – Various Levels
- Probabilistic Forecasting
  - How likely is the proposed budget to be fulfilled?
  - How likely are alternative scenarios?

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## Spending Plan vs. Budget

- *Language Matters...*
  - *Use language that is actionable and Positive NOT limiting language*
- Spending Plan - Design the life you want to live
- Budget - Cut out unnecessary expenses
- Spending Plan - Can be used as a roadmap for the future
- Budget - Used as a way to exclude options
- Spending Plan is actionable and positive
- Budget is limiting and negative

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## Common Wants vs. Needs

### Common Wants

- Large expensive home(s)
- Family expenditures
- "Folding money"
- Alternative medicine
- Unsuitable purchases → unusable by person with disability
- Suspect business ventures
- Irrational conservatism in investments
- Irrational risk taking in investments

### Common Needs

- Comprehensive, targeted therapies to improve the client's life
- Proper living arrangement & respectful domicile
- Adaptive equipment
- Electronic equipment
- Quality of life items
- Advanced medical procedures
- Effective counseling
- Trustee, attorney, other professional fees

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## Funding the Third Party SNT

- Good time to work with a financial advisor to provide advice to family on the lifetime costs of caring for person with a disability
- Life insurance is a good funding tool
  - It should be whole life, not term (if possible)
- Consider real estate
  - Mom and Dad's house to be used for the kid with a disability

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## Properly Administering SNT

- The best-drafted SNT is useless if a poorly performing trustee manages it incorrectly because
  - Will cause loss of public benefits
  - Will cause loss of assets
  - Ends up in litigation
- Trustee fails to read the trust document
- Trustee fails to set up a system for disbursements
- Failing to maintain good records of income and distributions

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## Ways to Stay Current on Special Needs Planning

- **California Special Needs Planning Symposium**

- Three-day California specific special needs program for financial advisors, attorneys, and trustees covering all aspects of special needs planning
- [www.SNTSymposium.com](http://www.SNTSymposium.com)



**SPECIAL NEEDS PLANNING**  
SYMPOSIUM  
MOVING TO MASTERY

- **Academy of Special Needs Planners (ASNP)**

- Members include financial advisors, attorneys, and professional trustees includes a national meeting, list serve, knowledge bank, and much more
- [www.specialneedsplanners.com](http://www.specialneedsplanners.com)



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**SPECIAL NEEDS PLANNING**  
SYMPOSIUM  
MOVING TO MASTERY

**Special Needs Planning Symposium**  
**February 9-11, 2023**


**Meritage Resort & Spa**  
**Napa, California**

**[www.SNTSymposium.com](http://www.SNTSymposium.com)**


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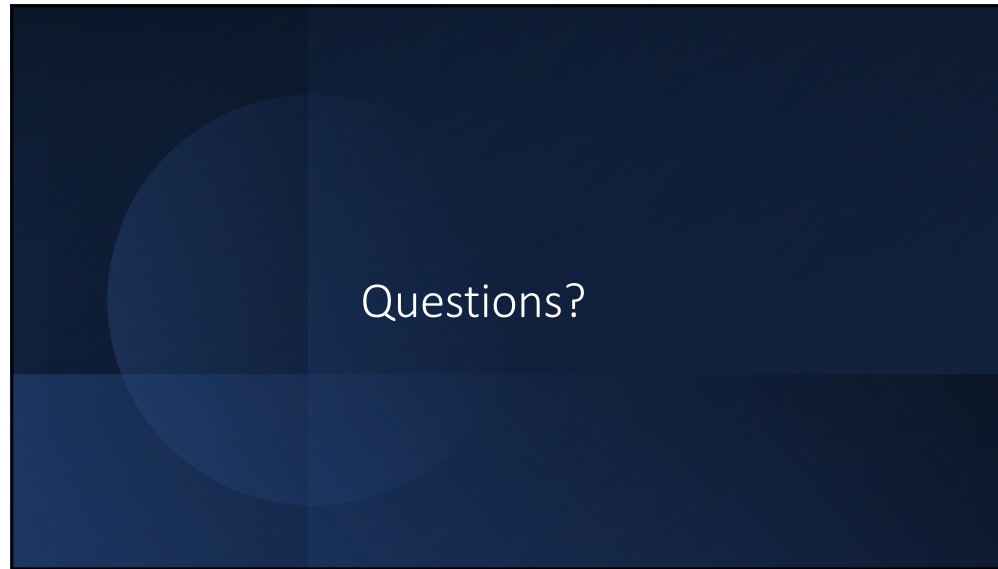
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## Ways to Stay Current

- Books & Guides:
  - California SNT trustee guide: *Administering the California Special Needs Trust (3rd Edition)*
    - [www.Amazon.com](http://www.Amazon.com)
  - CEB's Legal Treatise, *Special Needs Trusts: Planning, Drafting & Administration*
    - <https://store.ceb.com>
  - Nolo Press: *Special Needs Trusts: Planning for your Child's Financial Future*
    - [www.Nolo.com](http://www.Nolo.com)
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