

This workbook guides you through every critical decision in special needs trust planning. Use it to evaluate trust types, assess funding needs, select trustees, coordinate with ABLE accounts, and ensure your planning protects benefits while providing lifelong support.

SPECIAL NEEDS TRUST

Planning & Decision Workbook

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Protecting Government Benefits While Securing Your Child's Future

This workbook guides you through every critical decision in special needs trust planning. Use it to evaluate trust types, assess funding needs, select trustees, coordinate with ABLE accounts, and ensure your planning protects benefits while providing lifelong support.

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This workbook is provided for educational purposes. Always consult with qualified estate planning attorneys and financial advisors before making trust decisions.

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Read the full guide at: <https://memorialmerits.com/special-needs-trusts-explained/>

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SECTION 1: Current Benefit Inventory

Before planning a trust, document all current government benefits your child receives. Even small changes in assets or income can affect eligibility.

Supplemental Security Income (SSI)

- ☐ Currently receiving SSI?
- ☐ Monthly benefit amount: \$ _____
- ☐ Date benefits began: _____
- ☐ Asset limit: \$2,000 (cannot exceed)
- ☐ Income limit: \$ _____ (varies by state)

Medicaid/Medicare

- ☐ Currently receiving Medicaid?
- ☐ Currently receiving Medicare?
- ☐ Services covered: _____
- ☐ Asset limits for Medicaid: \$2,000 (in most states)

Other Benefits

- ☐ Social Security Disability Insurance (SSDI): \$ _____/month
- ☐ Housing assistance (Section 8, HUD): _____
- ☐ SNAP (food assistance): \$ _____/month
- ☐ State-specific disability benefits: _____

IMPORTANT: Assets held IN a properly structured special needs trust do not count toward the \$2,000 SSI/Medicaid limit. Assets held OUTSIDE the trust do count.

SECTION 2: First-Party vs Third-Party Trust Decision

The type of trust you need depends on WHERE the money is coming from. This is one of the most critical distinctions.

Factor	First-Party Trust	Third-Party Trust
Asset Source	Beneficiary's own assets (injury settlement, inheritance they already received)	Parent/family assets (your estate, life insurance, gifts)
When Needed	Child already has money in their name	You're planning ahead before death
Medicaid Payback	YES - State must be reimbursed for Medicaid expenses upon beneficiary's death	NO - Remaining funds go to your chosen beneficiaries
Age Requirement	Beneficiary must be under 65 when trust is created	No age restriction
Remainder Beneficiary	State gets reimbursed first, then designated beneficiaries	You choose who gets remaining funds (typically siblings)
Most Common For	Personal injury settlements, Workers' comp awards, Backpay SSI/SSDI	Parent's estate planning, Life insurance proceeds
Flexibility	More restrictions due to Medicaid payback	More flexible, no government claim

Which Trust Type Do You Need?

- ☐ Third-Party Trust (most parents creating estate plans need this)
- ☐ First-Party Trust (your child already has assets in their name that must be protected)
- ☐ Both (different asset sources require different trust types)
- ☐ Unsure (consult estate planning attorney - this is critical to get right)

CRITICAL: If someone leaves money directly to your child in a will or makes them a life insurance beneficiary, those funds become your child's assets and will likely disqualify them from SSI/Medicaid. You may need to establish a first-party trust through the courts to protect those assets. Prevent this by ensuring all family members leave inheritance to your third-party trust, NOT to your child directly.

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SECTION 3: Permitted vs Prohibited Trust Expenses

What the trust CAN and CANNOT pay for determines how effectively it supplements your child's benefits without causing disqualification.

✓ PERMITTED EXPENSES (Trust Can Pay For These)

- Medical/dental expenses not covered by Medicaid (vision care, dental work, copays)
- Therapy and rehabilitation services (physical therapy, occupational therapy, speech)
- Education and training (tutoring, vocational training, books, technology)
- Recreation and entertainment (vacations, hobbies, movies, concerts, sports)
- Electronic equipment (computers, tablets, smartphones, assistive technology)
- Home furnishings for beneficiary's room (furniture, bedding, decorations)
- Vehicle purchase and maintenance (if necessary for beneficiary's needs)
- Companion care beyond what Medicaid provides
- Clothing and personal items
- Professional services (care management, advocacy, legal representation)
- Burial expenses and funeral arrangements

✗ PROHIBITED EXPENSES (Will Reduce SSI Benefits)

These expenses count as "in-kind support" and reduce SSI by up to one-third:

- Food (groceries, meals, dining out)
- Shelter expenses (rent, mortgage, property taxes, homeowners insurance, utilities)
- Cash distributions directly to beneficiary (counts as income)

STRATEGY: If shelter costs \$1,200/month and your child's SSI is \$900/month, it may be worth having the trust pay shelter and accept the one-third SSI reduction (\$300). Your child still receives \$600 SSI + \$1,200 shelter = \$1,800 value. Discuss with benefits specialist.

SECTION 4: Trust Funding Needs Calculator

How much money does the trust need? This depends on your child's projected lifespan, anticipated needs, and what government benefits won't cover.

Annual Supplemental Expense Projection

- ☐ Medical/dental not covered by Medicaid: \$ _____
- ☐ Therapy and rehabilitation: \$ _____
- ☐ Recreation and entertainment: \$ _____
- ☐ Technology and equipment: \$ _____
- ☐ Education and training: \$ _____
- ☐ Clothing and personal items: \$ _____
- ☐ Professional advocacy/care management: \$ _____
- ☐ Transportation and travel: \$ _____
- ☐ Other supplemental needs: \$ _____

TOTAL ANNUAL SUPPLEMENTAL NEEDS: \$ _____

Lifetime Funding Calculation

- Child's current age: _____ years
- Estimated life expectancy: _____ years
- Years of projected need: _____ years

- Annual supplemental needs: \$ _____
- × Years of need: _____ years
- = Basic funding target: \$ _____

- Add 30% for inflation/contingencies: \$ _____

- **TOTAL RECOMMENDED TRUST FUNDING:** \$ _____

REALITY CHECK: If your child needs \$10,000/year in supplemental support for 50 years, that's \$500,000 minimum funding. Most families use life insurance to create this corpus affordably. A 40-year-old in good health might obtain \$500,000 in term life insurance for \$40-60/month. Permanent insurance costs more but builds cash value.

SECTION 5: Trustee Selection & Evaluation

Your trustee will manage these funds for your child's entire life. This is one of the most important decisions in your estate plan.

Essential Trustee Qualities

- ☐ Understanding of SSI/Medicaid benefit rules
- ☐ Financial responsibility and integrity
- ☐ Organized and detail-oriented
- ☐ Willingness to serve for decades
- ☐ Puts beneficiary's interests first
- ☐ Can handle family pressure/requests
- ☐ Responsive and communicative
- ☐ Located reasonably close to beneficiary (or willing to use care managers)

Trustee Candidate Comparison

Consideration	Candidate 1: _____	Candidate 2: _____	Professional Trustee
Understands benefit rules?			
Financial responsibility?			
Age/health status?			
Relationship with child?			
Organizational skills?			
Current obligations?			
Location/proximity?			
Family dynamics?			
Compensation needed?			
Backup if unable?			
Overall suitability (1-10 scale)			

Professional Trustee Considerations

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When a professional or corporate trustee makes sense:

- No suitable family members available
- Family conflicts or concerns about fairness
- Complex asset management required
- Large trust (>\$500,000) needing sophisticated management
- Family trustee needs professional support (consider co-trustee arrangement)
- Want neutral party to handle difficult family dynamics

Professional trustee fees:

☐ Typical fee: 1-2% of trust assets annually

☐ Minimum annual fee: \$_____

☐ Setup/acceptance fees: \$_____

CONSIDER: Co-trustee arrangements can combine family member's personal knowledge with professional's expertise. For example: sibling handles day-to-day needs, professional handles investments and compliance.

SECTION 6: ABLE Account Coordination

ABLE accounts (tax-advantaged savings for people with disabilities) can work alongside special needs trusts. Understanding how they differ helps you use both effectively.

Factor	ABLE Account	Special Needs Trust
Contribution Limit	Annual gift tax limit (\$18,000 in 2024)	No limit
Total Asset Limit	First \$100,000 doesn't count toward SSI, but state Medicaid limits may apply	No limit
Medicaid Payback	YES (similar to first-party trust)	Only for first-party trusts
Who Can Contribute	Anyone	Depends on trust type
Permitted Expenses	Broader - can pay for food and shelter without SSI reduction	Cannot pay food/shelter without SSI reduction
Control	Beneficiary can have direct access if capable	Trustee has full control
Setup Complexity	Simple - like opening a bank account	Requires attorney and legal documents
Best For	Smaller amounts, qualified disability expenses, beneficiary has some capacity	Large amounts, long-term planning, beneficiary needs full protection

Optimal Use Strategy

- ☐ Use ABLE for annual expenses you want child to access (up to \$18,000/year)
- ☐ Use special needs trust for larger amounts and long-term security
- ☐ Trust can distribute to ABLE account when beneficiary needs funds for qualified expenses
- ☐ ABLE covers food and shelter without SSI penalty (unlike trust)

STRATEGY: Many families fund ABLE accounts for short-term needs (assistive technology, education, small expenses) while special needs trusts hold larger amounts for lifetime security. The trust can make annual distributions to the ABLE account as needed.

SECTION 7: Coordinating with Family Estate Plans

Everyone in your family who might leave money to your child must understand they cannot leave assets directly to your child without jeopardizing benefits.

Family Members Who Need to Update Their Plans

1. 1. **Parents (you and spouse):** Will must leave inheritance to special needs trust, not directly to child
2. 2. **Grandparents:** Must name your child's trust as beneficiary, not child directly
3. 3. **Siblings:** Should understand they cannot leave inheritance directly to special needs sibling
4. 4. **Aunts/Uncles:** Need clear instructions on how to leave gifts (through trust only)
5. 5. **Life Insurance Policies:** Beneficiary must be the trust, not your child
6. 6. **Retirement Accounts (401k, IRA):** Consider trust as beneficiary (discuss tax implications with advisor)
7. 7. **Investment Accounts:** Transfer on Death (TOD) designations must name trust, not child
8. 8. **Real Estate:** Property left to child directly can disqualify benefits - use trust

Important Conversations to Have

- ☐ Explain to grandparents why they CANNOT name your child as direct beneficiary
- ☐ Provide trust name and EIN to family members updating their estate plans
- ☐ Discuss with siblings how to balance inheritance if one sibling has special needs trust
- ☐ Ensure godparents/other caregivers understand benefit protection requirements
- ☐ Share letter of intent with family members who will be involved in child's care

CRITICAL: A well-meaning grandparent who leaves \$50,000 directly to your child can instantly disqualify them from SSI and Medicaid. You'll then need to spend down the inheritance or establish a first-party trust through the courts (expensive and time-consuming). Prevention through proper planning is essential.

SECTION 8: Letter of Intent Outline

A letter of intent is a non-legal document that provides guidance to your trustee, guardian, and other caregivers about your child's needs, preferences, and your wishes for their care.

Essential Information to Include

1. **Medical History & Current Needs** - Diagnoses, medications, doctors, specialists, allergies, medical equipment, therapy schedules
2. **Daily Living Routine** - Wake/sleep schedule, meal preferences, personal care needs, sensory sensitivities
3. **Communication Style** - How your child communicates, what behaviors mean, how to de-escalate situations
4. **Educational/Vocational Info** - Current school/program, IEP accommodations, learning style, strengths and challenges
5. **Social & Recreational** - Friends, activities they enjoy, community involvement, religious/cultural practices
6. **Living Arrangements** - Current living situation, future preferences (group home, with family, supported living)
7. **Financial Overview** - Government benefits, trust distributions, how money should be used, spending priorities
8. **Relationships & Support Network** - Key people in their life, who should be involved in decision-making
9. **Future Goals & Wishes** - Your hopes for their quality of life, independence, community integration
10. **End-of-Life Wishes** - Medical directives, funeral preferences, burial arrangements

- ☐ Draft letter of intent
- ☐ Share with trustee and guardian
- ☐ Review and update annually
- ☐ Store with estate planning documents

REMEMBER: The letter of intent is not legally binding, but it's invaluable for anyone stepping into a caregiving role. It preserves your knowledge and wishes when you're no longer there to advocate for your child.

SECTION 9: Implementation Action Plan

Use this timeline to guide your special needs trust creation process.

Phase 1: Information Gathering (Week 1-2)

- ☐ Complete Section 1: Current Benefit Inventory
- ☐ Complete Section 4: Trust Funding Needs Calculator
- ☐ Gather all current estate planning documents
- ☐ Collect SSI/Medicaid award letters and benefit details
- ☐ List all assets that will fund the trust (life insurance, investment accounts, etc.)
- ☐ Identify potential trustee candidates

Phase 2: Professional Consultation (Week 3-4)

- ☐ Schedule consultation with special needs estate planning attorney
- ☐ Bring completed workbook sections and benefit documentation
- ☐ Discuss first-party vs. third-party trust needs
- ☐ Review trustee options and make selection
- ☐ Get fee quote and timeline for trust creation
- ☐ Ask about ABLE account setup if appropriate

Phase 3: Trust Creation (Week 5-8)

- ☐ Attorney drafts trust document
- ☐ Review trust document carefully
- ☐ Sign and notarize trust document
- ☐ Obtain Trust EIN (Employer Identification Number) from IRS
- ☐ Open trust bank account
- ☐ Begin funding trust (life insurance beneficiary changes, asset transfers)

Phase 4: Coordination & Communication (Week 9-12)

- ☐ Update your will to coordinate with trust
- ☐ Change life insurance beneficiaries to the trust
- ☐ Update retirement account beneficiary designations (discuss tax implications)
- ☐ Notify family members about the trust and how to leave gifts
- ☐ Provide trust information to grandparents, siblings, etc.
- ☐ Draft letter of intent for trustee and guardian
- ☐ Set up ABLE account if using alongside trust
- ☐ Store all documents securely and inform trustee of location

Phase 5: Ongoing Maintenance (Annual)

- ☐ Review trust funding levels annually
- ☐ Update letter of intent as child's needs change
- ☐ Confirm trustee is still willing and able to serve
- ☐ Review beneficiary designations on all accounts
- ☐ Assess whether trust provisions still meet needs
- ☐ Consult attorney if laws or benefit rules change
- ☐ Update trust document if family circumstances change significantly

SECTION 10: Professional Contacts & Resources

Estate Planning Attorney

Name: _____

Firm: _____

Phone: _____

Email: _____

Date trust created: _____

Trustee

Name: _____

Relationship: _____

Phone: _____

Email: _____

Backup Trustee: _____

Benefits Specialist/Advocate

Name: _____

Organization: _____

Phone: _____

Email: _____

Financial Advisor

Name: _____

Firm: _____

Phone: _____

Email: _____

Trust Account Information

Bank Name: _____

Account Number: _____

Trust EIN: _____

Account Opening Date: _____

ABLE Account Information

State Program: _____

Account Number: _____

Current Balance: \$ _____

Final Reminders

- This workbook is a living document. Review and update it annually.
- Store completed workbook with your estate planning documents.
- Ensure your trustee, guardian, and attorney have copies.
- Laws and benefit rules change. Review your plan when regulations update.
- Life changes (marriage, divorce, new children, trustee changes) require trust review.
- Never leave assets directly to your child - always through the trust.
- Keep communication open with family members about the plan.
- The trust is only effective if properly funded. Follow through on beneficiary changes.
- Consider consulting a benefits specialist before making major distributions.
- Your careful planning today provides security for your child's lifetime.

The work of creating a special needs trust is challenging. It requires confronting difficult realities and making complex decisions. But this planning provides irreplaceable protection and peace of mind. Your child's future security depends on the decisions you make today.

For additional resources, support, and guidance:

Visit MemorialMerits.com

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