

Planning for a Loved One With Special Needs

Ronald C. Morton
Certified Elder Law Attorney



MEMBER OF THE ACADEMY OF
SPECIAL NEEDS
PLANNERS



Disclaimer

The following presentation is meant for education only and not meant as a substitute for legal counseling.

Why Plan?

Planning for a loved one with special needs is about enhancing that person's quality of life to the maximum extent possible and protecting them only as much as necessary to not limit or restrict their potential.

Benefits of Planning

1. Provide Financial Security
2. Leverage Means Tested Public Benefits
3. Select Proper Team to Provide Lifetime Management
4. Plan for Appropriate Housing
5. Provide Ongoing System for Advocacy
6. Plan for Caregiving Needs
7. Coordinate Entire Extended Family's Planning
8. Protect Beneficiary from Predators
9. Preserve Assets for other Heirs

Successful Planning Includes

- Having the right team of advisors to advocate for the needs of your disabled loved one
- Making sure your plan has the flexibility to deal with issues in a changing environment

Part 1: Creating an Effective Plan for Your Loved One



What Steps Should You Take Today?

Envision Your Loved One's Future

Planning ahead makes all the difference:

- Where and with whom will your loved one live
- What type/level of care will be required?
- Will a conservator or guardian be necessary?
- Who else will be involved?
- What kind of lifestyle is desired?
- Consider potential future challenges?

What Steps Should You Take Today?

Create a Memorandum of Intent

Lays out goals/expectations:

- Details preferences, needs, wishes, both medical and personal
- Lists key people in loved one's life

Helps guide:

- Family members
- Trustee
- Caregivers
- Others



What Steps Should You Take Today?

Estimate Income and Expenses

- Monthly income:
 - SSI, SSDI, Social Security, earned/unearned income

Monthly living expenses:

- Housing, food, transportation, medical, recreation, etc.
- Consider how any shortfall will be met

Special Needs Expense Information

Item	Beginning		Amount		Lasting	
	Today	At Age	Monthly	Annual	Lifetime	Until Age
<u>Housing:</u>						
Mortgage/ Property Taxes						
Rent Expense						
Home/Condo Maintenance Fees/Security System						
Utilities (fuel/electricity/gas)						
Telephone/Cell Phone						
Cable/Satellite/Internet						
Misc. Household (lawn/etc.)						
<u>Child Care:</u>						
<u>Special Care Needs:</u>						
Live-in aid or ADL						
Assistance & Respite						
Advocacy/Social Services						

Item	Beginning		Amount		Lasting	
	Today	At Age	Monthly	Annual	Lifetime	Until Age
<u>Transportation:</u>						
Automobile/Van						
Fuel/maintenance of auto/van						
Adaptive Equipment						
<u>Nutrition/Food/Beverage:</u>						
Food/Beverages						
Special Diet						
Vitamins/Oral Medications						
Feeding Devices						
Eternal/Nutrition/Misc.						
<u>Clothing:</u>						
Special Clothing						
Cleaning Laundry						
<u>Furnishings:</u>						
Medical Equipment						
Wheelchair/Ramps						

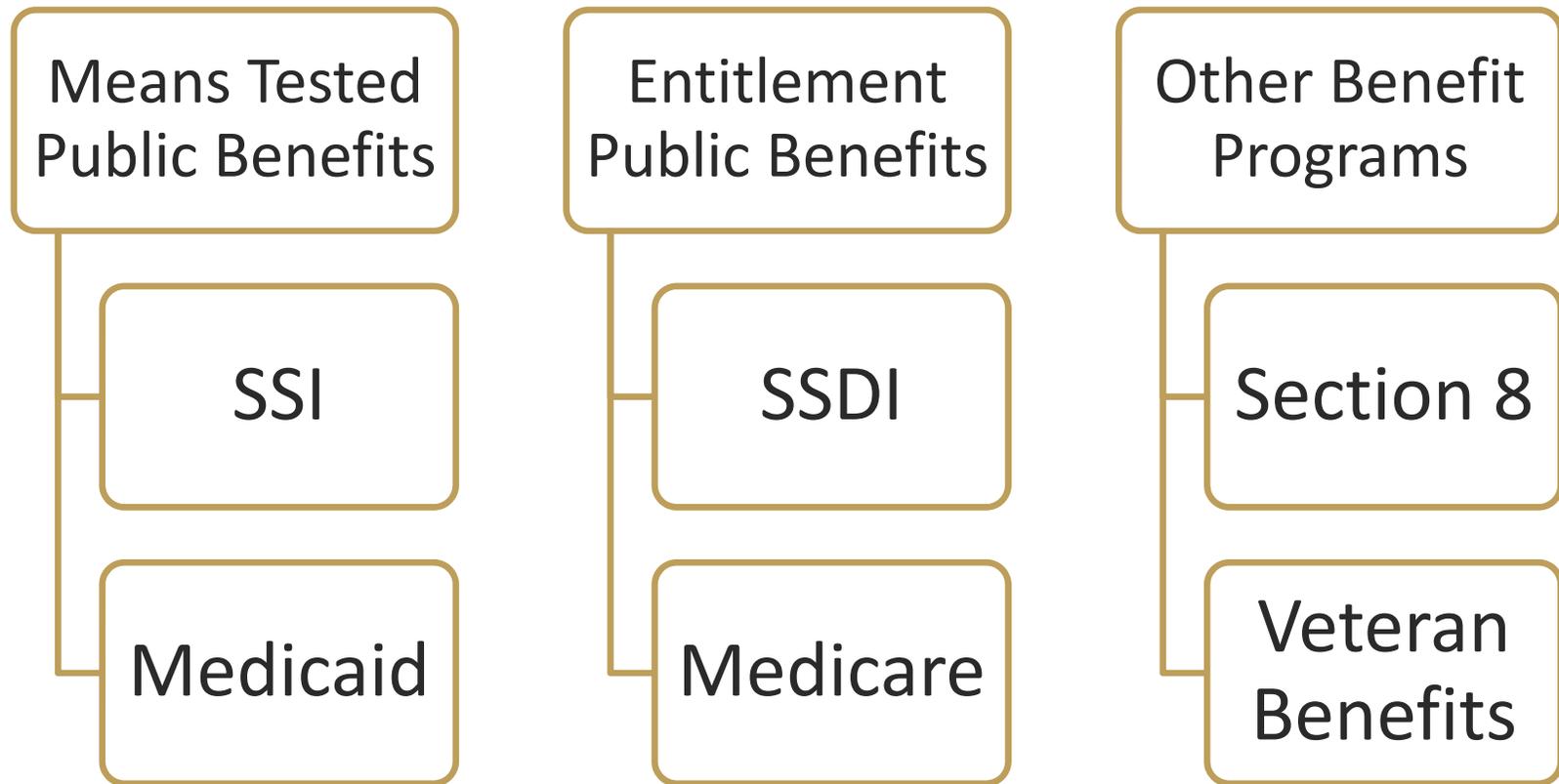
Planning for Loved One's Incapacity

- Sign Advance Health Care Directives and Powers of Attorney, if legal capacity
- Consider Conservatorship/Guardianship, if lacks capacity:
- When child without mental capacity becomes an adult and parents want to maintain legal responsibility
- Court appoints conservator/guardian

Part 2: Understanding Public Benefits



Public Benefits At a Glance



Supplemental Security Income (SSI)

- Person Must Meet Two Tests:
 - Medically Disabled (physically or mentally) or elderly (65+), plus
- Poor
 - Resource Test –measured only one time each month
 - Income Test – total any income received any time of the month

Disability Defined

- “Disability” for an adult is defined as the inability to engage in any “substantial gainful activity” (SGA) 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
- “Disability” for a minor is defined as a medically determinable physical or mental impairment or combination of impairments that causes marked and severe functional limitations, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of not less than 12 months



SSI Resource Test

“Countable resource” limits for SSI are:

- \$2,000 for an eligible individual and
- \$3,000 for an eligible couple

Not all resources are counted, some are exempt:

- Home of any value
- Automobile of any value
- Furniture, clothing, and personal care items
- Burial plots, certain types of life insurance contracts, and miscellaneous other assets

SSI – What Do You Get?

SSI is to pay for food and shelter

- In 2019, Federal Benefit Rate is \$771/month
- Some States Supplement, e.g. California is \$156.40
- Amount may change depending on living arrangement or eligible couple

Types of SSI Income

Unearned Income

Includes gifts, payments from annuities, and pensions, alimony and support payments, dividends, interest, rents, awards and payments from other benefits programs.

Reduces benefits dollar-for-dollar after the first \$20.00

Earned Income

Consists of wages, royalties, net earnings from self employment, and any honoraria received for services rendered.

Reduces benefits one dollar for every two dollars earned after the first \$65 earned monthly.

Types of SSI Income

In-Kind Support & Maintenance

Actual receipt of food, clothing, or shelter, or something that can be used to get one of these.

Reduces benefits dollar for dollar up to a maximum of 1/3 the benefit.

Deemed Income

Someone else's income. (Same household; duty to support)

Reduces benefits dollar-for-dollar after the first \$20.00

SSDI Eligibility

Two tests to qualify:

1. Disability – Same definition as for SSI
2. Sufficient work history

No resource test for SSDI

- SSDI benefit based on past wages
- After 24 months = Medicare
- Can receive SSDI and SSI if wages were low

Childhood Disability Beneficiary (CDB) (sometimes called) Disabled Adult Child

- Social Security for individuals:
 - Disabled before age 22 and
 - With parents eligible based on their work record who are retired, disabled or deceased
 - 50% of parent's RSDI while living
 - 75% of parent's RSDI after death
- Social Security benefits may reduce or eliminate SSI benefits
- No resource test
- Medicare after 24 months

Medicaid and Medicare

Medicaid:

- Covers “medically necessary” services, equipment, hospitalization, prescription meds
- Preventative care
- Covers long-term care and in home nursing care
- Medicare:
- Medical coverage, including doctors, hospital, prescription meds

Medicaid and Medicare

Medicaid

- Automatically available with SSI
- Must Apply Separately with SSDI or SS
- Expanded Medicaid if income below 138% FPL

Medicare

- Available with SSDI and CDB after 24 months

Section 8

Housing is one the greatest concerns that persons with disabilities and their families have for the future

Housing

Section 8 and Special Needs Trusts

- Rules issued by HUD
- Administered by local Public Housing
- Voucher Program vs. Project Based Assistance
- Not an entitlement benefit



Housing

Qualifying for Section 8

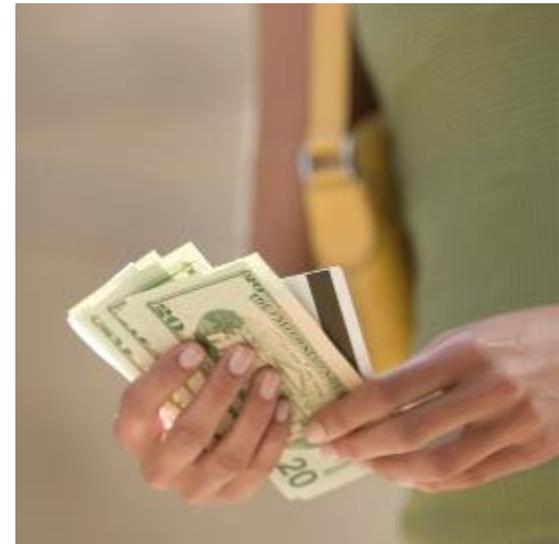
- Income limits
 - www.huduser.org
- Asset Test
- Transfer for less than fair market value
- Applying for Vouchers
 - Waiting lists
 - First come vs. Lottery
 - May take years to get



Housing

Special Needs Trust Issues:

- Regular recurring distributions may be problematic
 - Cell Phone, Cable, Internet
- Common exclusions
 - Sporadic income/gifts
 - Reimbursement of medical expense
 - Benefit back-pay, settlements, lump-sum inheritance



Housing

Purchasing a home

- Allowable
- Should be sustainable
- Consider money, management, safety, and support



Part 3: Special Needs Trust and ABLE Account



Types of Special Needs Trusts

	Source of Funds	Who Establishes	Distribution Upon Death
Third Party	Anyone except beneficiary	Anyone except beneficiary	Grantor's wishes
(d)(4)(A)	Disabled beneficiary's funds before age 65	Individual/Beneficiary, Parent, grandparent, Guardian, Court	Medicaid payback; then remainder beneficiaries
(d)(4)(C) Pooled Trust	Disabled beneficiary's funds	Individual/Beneficiary, parent, grandparent, Guardian, Court	Non-profit Trustee; <i>or</i> , Medicaid payback; then remainder beneficiaries

Utilizing a Third Party Special Needs Trust

- A Third Party Special Needs Trust is the best method for providing instructions on leaving inheritance to a loved one with special needs
- Called a third party SNT because it is established with the assets of someone other than loved one with special needs

Other Arrangements - Not Recommended

- Outright inheritance – loss of SSI and Medicaid
- Left in non-qualifying trust – loss of SSI and Medicaid
- Disinheritance – no money available for loved one with special needs
- Leaving assets to brothers or sisters with request to take care of sibling
 - Subject to 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

Third-Party Special Needs Trust

Third-party trust main requirements:

- Beneficiary (or spouse) did not create the trust.
- The trust does not hold any of the Beneficiary's (or spouse's) own money.
- The Beneficiary is not trustee and Trustee has sufficient discretion to withhold distributions

Third-Party Special Needs Trusts

Most families prefer third-party trusts:

- No payback requirements
 - Grantor can leave any remaining funds to whomever he or she wants
- Revocable during life of grantor
- More drafting flexibility so long as correct distribution standard is used

Choosing The Trustee

- Family vs. Professional vs. Attorney
 - Complexity-SSI rules, tax reporting, investments,
 - Amount under management
 - Court oversight - bond?
 - Family relationship
 - Fees
 - Conflict of interest
 - Knowledge and experience
 - Ability vs. willingness

Using Trust Advisory Committee and Trust Protector

Consider Using:

- **Trust Advisory Committee**
 - Name Family/Friends to Make Sure Trustee doing job
- **Trust Protector**
 - Provide Authority to make modifications if change in law or situation

Trustee Duties



What Can a SNT Pay For?

How does the expenditure affect beneficiary's government benefits?

Is the expenditure appropriate for the beneficiary and consistent with trust policies?

Is the expenditure at fair market value and otherwise reasonable?

How Much Should I Fund

Most People Fall Into Two Groups:

1. Treat All Kids Equally
2. Fund Loved One with Special Needs with More Because Unable to Work
 - Life Insurance is good funding tool
 - Must use special planning for retirement assets
 - Find good financial planner

First-Party Special Needs Trusts

First Party SNTs are the only planning tool that allows an individual who has assets to preserve those assets AND preserve eligibility for needs-based public benefits

First-Party SNTs are called:

- (d)(4)(A) SNT (a/k/a Litigation or Payback SNT)
- (d)(4)(C) SNT (a/k/a Pooled Trust)

First Party SNTs

When are First Party SNTs commonly used:

- Personal Injury Award
- Inheritance or Gift
- Minor with a Disability Turns 18
- Adult Recently Disabled

The ABLE Account

- Achieving a Better Life Experience (ABLE) account
 - Passed into law on December 18, 2014
 - Similar to 529 Plan Educational Plans but for persons with disabilities
 - As described in following charts, person can fund his or her own ABLE account, yet there are several restrictions on it

ABLE Account

Issues	ABLE Account
Who can use?	Only persons disabled before age 26
Who can fund?	Anyone, including person with a disability
How many can person have?	One
Who can control?	Person with a disability and likely their legal guardian, conservator, or agent
Who inherits on death of person with disability	Medicaid first, then can go to heirs

ABLE Account

Issues	ABLE Account
How much can fund in a year?	\$15,000 (or annual gift exemption)
Is funding gift-tax free?	Yes
Is there a cap on how much can be in account?	Yes, currently \$100,000 limitation for SSI recipients and up to State 529-plan limitations
How is income taxed?	No income tax
What type of distributions can be made?	Only “qualified disability expenses” as defined by government

Part 4: Guardianship/Conservatorship



Guardianship/Conservatorship

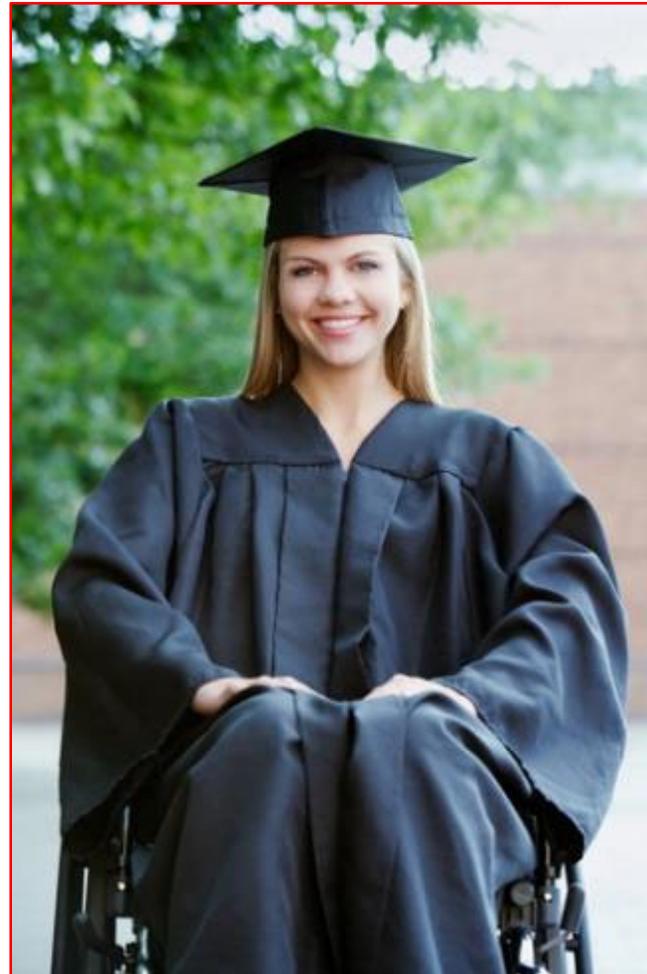
- At age 18, an individual is presumed to have legal capacity
- If loved one lacks capacity to manage personal or financial affairs a court appoints a guardian or conservator to take control over that person's affairs

Guardianship/Conservatorship

There are two general types of Guardianship/Conservatorship:

- Of the Person
 - has the care, custody, control, and education of the person; and
- Of the Estate
 - must manage finances and legal affairs

Part 5: Making Decisions About the Future



What You Should Do

- Create Memorandum of Intent
- Establish own Estate Plan
- Establish Special Needs Trust
- Calculate future financial need
 - Consider funding alternatives, e.g. life insurance
- Name SNT as beneficiary of retirement accounts
 - Special considerations

Case Study: Nathan

Current situation:

- Just turned 18-year-old, has autism and lacks capacity
- Lives with mom and dad
- Income from SSI
- Limited personal assets (clothing, t.v.)
- Beneficiary of Uniform Transfer Minor's Act Account available to him at age 21 and worth around \$25,000
- Qualifies for Medicaid

Case Study: Nathan

Future situation:

- How to preserve public benefits?
- Who will make health care decisions?
- Who will make financial decisions?
- Where will he live?
- How will his medical expenses be paid?
- Who will advocate for care, employment, or schooling?

What Plan Could Nathan's Parents Make?

- Make no decisions/plans
- Leave money to Nathan
- Disinherit Nathan
- Leave money to siblings with promise to help
- Establish third-party SNT for Nathan
- Establish first-party SNT for Nathan/ Spend down Assets
- Establish Limited Conservatorship

Get Started Today

- Understand your loved one's public benefits
- Make plans for the future
- Start naming those persons who will advocate and care for your loved one
- Make the Special Needs Trust the key part of your estate plan
- Talk to an Attorney who Specializes in this Complicated Area of Law

Thank You

Ronald C. Morton

Certified Elder Law Attorney

402 E. Main St.

Clinton, MS 39056

(601)925-9797

www.mortonelderlaw.com



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