

# Special Needs: Caring for Loved Ones Under Unique Circumstances

*Let's build your child's future.*



# Presented by:

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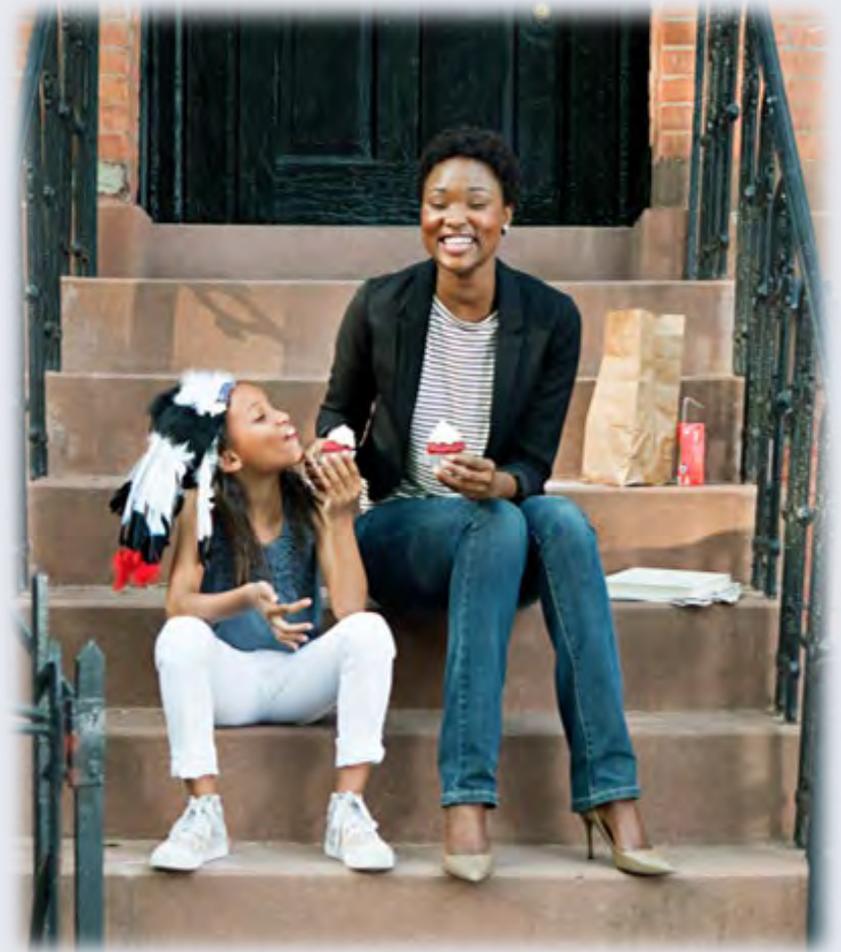
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# Your Special Needs Minor Child

Having children changes your life, however, having a child with special needs can bring:

1. Added challenges
2. Unique joys
3. Complex financial and emotional concerns



# Caring for a Special Needs Child Requires:



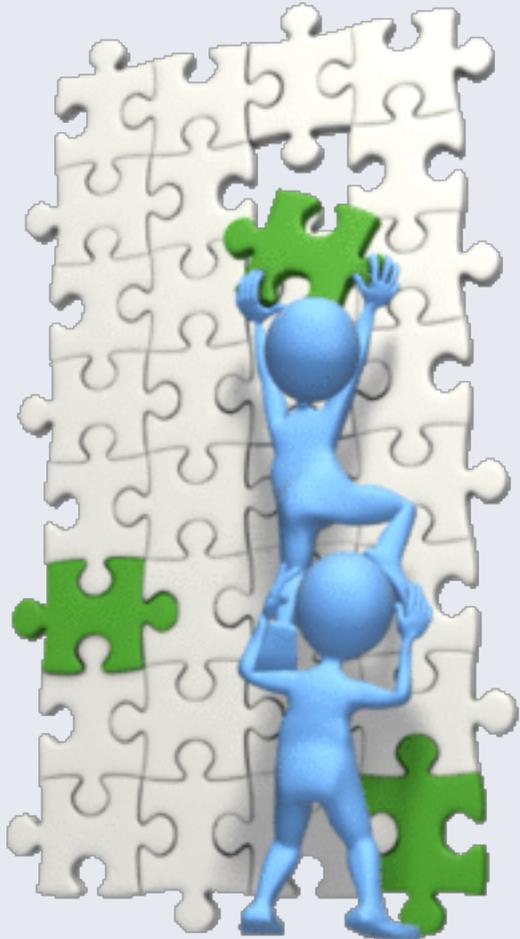
- Unique Support Systems
- Amazing Patience
- Dedication
- Unique Skills
- Special Planning
- Additional Resources
- A Balancing Act

# Core Planning Goals

- Provide lifetime care
- Ensure their quality of life
- Protect and maximize gov't benefits
- Select second generation caregiver
- Create peace of mind for you



# Additional Challenges for Parents



- Planning for a “three-person retirement”
- Providing equitably for all of your children
- Minimizing the impact of taxes

# Special Needs Planning is Different from General, Financial, and Estate Planning

**Legal**



**Government Benefits  
and Care Management**



**Financial**



# Common Planning Problems

- Lack of coordination among professional advisors
- Many advisors are not experts in special needs planning
- Your plan is obsolete or ineffective
- You are not certain that a special needs plan is needed
- Procrastination



# Is Government Assistance Available?

- Explore Federal & State Programs
  - National Institute of Health – [www.nih.gov](http://www.nih.gov)
  - Social Security – [www.ssa.gov](http://www.ssa.gov)
  - Medicare/Medicaid (programs vary by state)
    - [www.medicare.gov](http://www.medicare.gov) and [www.cms.org](http://www.cms.org)

# Can You Qualify?



- Qualify – for what?
  - SSI (Supplemental Security Income)
  - Medicaid
  - Medicare
- When to qualify?
  - Now
  - Future

# SSI and Medicaid

- Supplemental Security Income (SSI)
  - Program for “needy,” disabled individuals
  - Qualifying for SSI may make the individual “categorically eligible” for Medicaid in many states

# SSI Definition of Disabled Child:

*“... child must have a medically determinable impairment that causes marked and severe functional limitations. The impairment must have lasted or be expected to last for a continuous period of at least 12 months or be expected to result in death.”*

# SSI and Medicaid

- These programs do not just consider income of disabled *child*
- Income and resources of *parents* are considered too
- Not all of the parents' income is counted



# Monthly SSI payments are made to qualified, disabled individuals with limited income and resources:

	Monthly Pmt. <sup>1</sup>	Resource Limits <sup>2</sup>
<b>Individual</b>	<b>\$794</b>	<b>\$2,000</b>
<b>Couple</b>	<b>\$1,191</b>	<b>\$3,000</b>

## Excluded Monthly Income

<b>Earned Income</b>	<b>\$65</b>
<b>Unearned Income</b>	<b>\$20</b>

<sup>1</sup>Source: Social Security Administration at [www.ssa.gov](http://www.ssa.gov) for 2021, most states. Amounts listed are highest federal SSI monthly payments allowable.

<sup>2</sup>Adjusted annually.

# SSI , Medicaid and Medicare

Qualifying for SSI will also qualify the individual for Medicare, and Medicaid in most states

## Medicare

- Run by Social Security Administration
- May pay health care costs of disabled child
- Who has received benefits for 2 years.

## Medicaid

- Administered by State
- Strict Income Eligibility Requirements
- Inclusive Coverage

# Individuals with Disabilities Education Act (IDEA)

The Act requires that children with disabilities receive:

- Free, appropriate public education
- As close to home as possible with children who do not have disabilities
- Supplemental services (speech therapy, advocates, classroom aides, interpreters)
- An assessment to determine the child's needs

# Qualify Today or in the Future?

- What can you afford to cover today?
- Do you need government assistance today?
- Will your child need it in the future?



# While your child is a minor:



- Government Benefits based on Child's definition of disability
- ABLE Accounts
- IDEA

# ABLE Accounts – What are they?

- Tax Advantaged Savings Accounts for disabled individuals
- Disability onset must be before age 26
- Income Earned by ABLE account is NOT taxed
- One account per person
- Anyone can Contribute
- Max Annual Contribution \$15,000 total
- First \$100,000 Exempt for SSI \$2,000 Resource Limit

# Planning for the Future

- Planning for the future can:
  - Protect against financial hardships
  - Help the child qualify for benefits after the death of his or her parents or guardian



# What Happens When a Parent, Guardian or Caregiver Dies Without Planning?

- Property may go directly to special needs child.
- This may disqualify them from government assistance
- Government assistance programs only cover basics
  - Food, clothing, shelter
- These benefits are provided at or below poverty level

# Not Covered by Government Assistance:

- Visits to relatives
  - Vacations
  - Entertainment
  - Furniture, TV, computer
  - Personal care items
  - Attendants, escorts or advocates
- Eyeglasses
  - Transportation
  - Rehabilitation
  - Essential dietary needs
  - Hobbies, recreation
  - Extraordinary medical expenses

# Suppose You Have Two Children...

- One has special needs.
- One does not.
- At your death, you want to treat your children fairly
- You have two choices
  - The government's plan
  - Your Plan



# Suppose...

- You have a \$500,000 estate
- Your two children, Zack and Dylan each get ½ of your estate
- You have no special needs planning in place

Zack has special needs.

- He uses his inheritance for services that **could have** been covered by government programs if his parents had done special needs planning

Dylan does not have special needs. He:

- Pays off his house,
- Buys a car,
- Takes a vacation,
- And saves some of his \$250,000

# Does This Seem Fair?

If not, would it make sense to leave the entire inheritance to Dylan and have Dylan take care of Zack?



# Will Dylan be Able to Take Care of Zack?

What if Dylan. . .

- Gets married?
- Has kids?
- Gets divorced?
- Has creditors?
- Gets sued?
- Becomes disabled?
- Doesn't handle money well
- Needs the money himself?
- Dies

*Is this really a better solution?*

# Is This Really the Best Solution?



- The psychological and emotional pressure on Dylan to take care of Zack can be taxing.
- What other options exist to help Dylan take care of Zack?

# Financial Issues

- Financial demands can be immediate and intimidating
- Even worse if a guardian must leave the workforce to care for loved one or hire a caregiver
- What if a guardian can't face these issues and leaves?

# Additional Steps to establish the trust

- Consult a Financial Adviser to determine the future financial needs
- Decide when the trust should be funded – now or at your death
- Determine how to fund your trust
  - Cash
  - Real Estate
  - Stocks, Bonds, Mutual funds
  - Life Insurance



Special Needs  
Trust

# How Special Needs Trusts Work During Parents' Life



Disabled Child Meets Needs  
Test Government Benefits  
Provide Basics

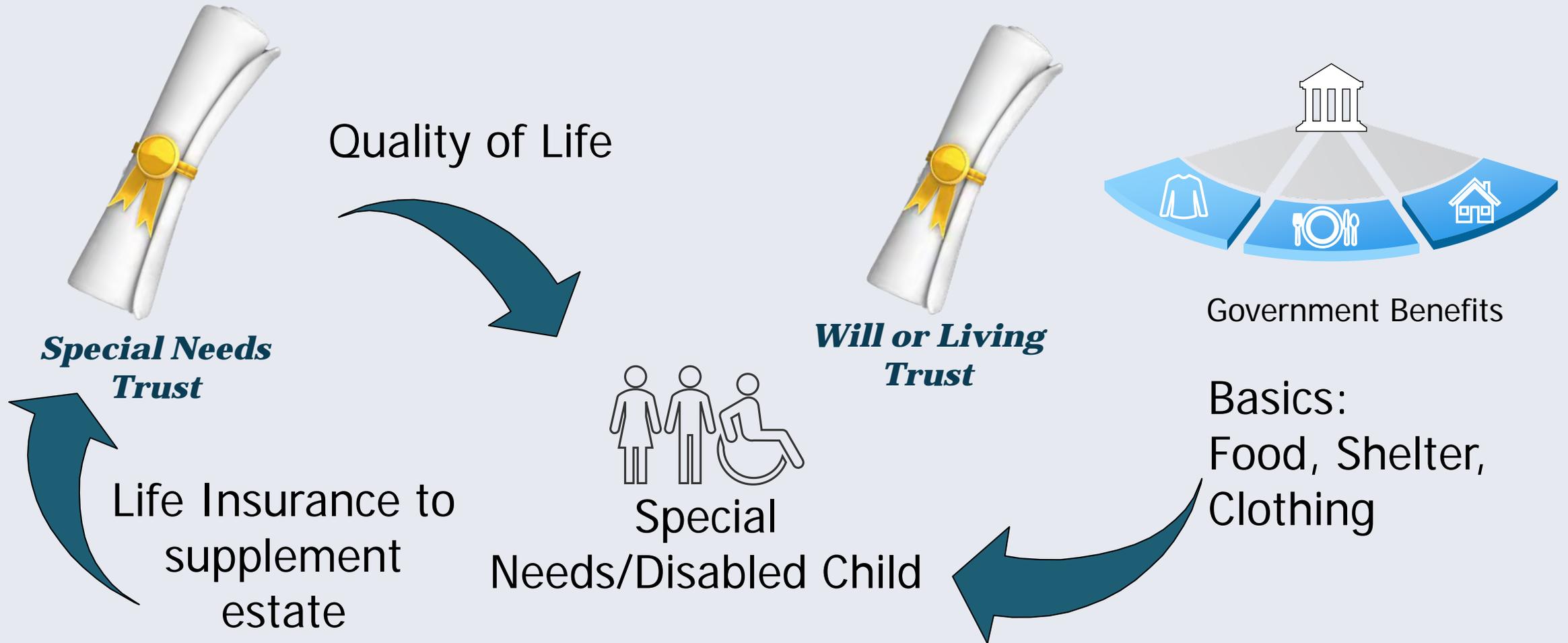


Gifts & Long-Term  
Funding to provide  
quality of life extras

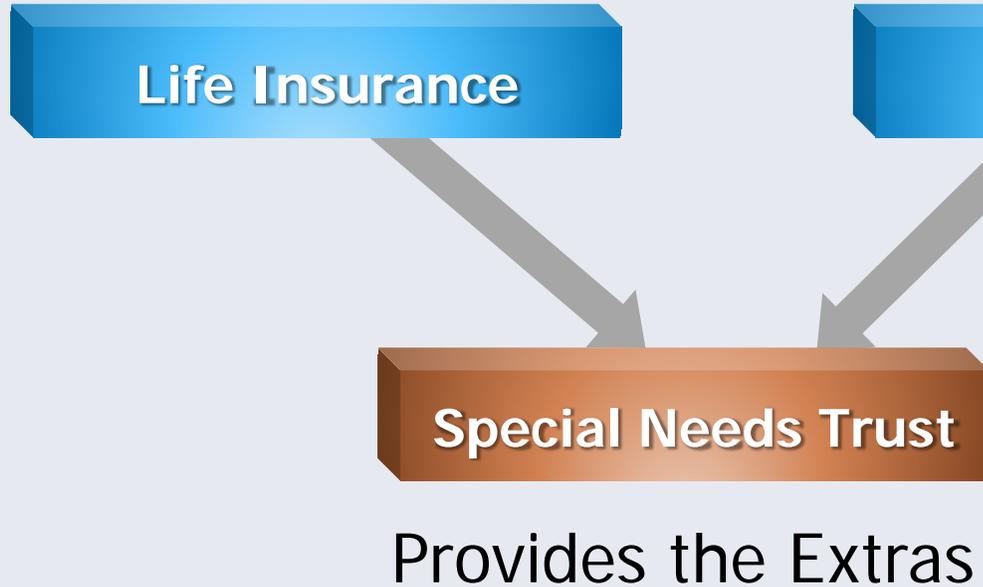


Disabled child does not meet  
needs test, parents will  
provide basics plus extras

# How Special Needs Trusts Work After Parents Death



# How Special Needs Trusts Work After Parents Death



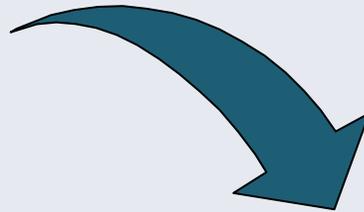
Government Benefits Provide  
Food, Shelter, & Clothing

# How Special Needs Trusts Work After Death of Special Needs Child



***Special Needs  
Trust***

Balance of Trust Assets



Other Heirs or Charity

# Getting Started

Retain an experienced attorney specializing in special needs planning  
Familiarize yourself with the assistance and resources available to you



# Who Can Draft a Special Needs Trust?

- Consult an Attorney who specializes in special needs planning

National Academy of Elder Law Attorneys, [www.naela.org](http://www.naela.org)

Special Needs Alliance, [www.specialneedsalliance.org](http://www.specialneedsalliance.org)

# Guidelines for Choosing Counsel

- Experienced Estate Planning Attorney
- Specializes in special needs planning
- Knowledgeable of state and federal assistance programs
- Understands SSI and state specific Medicaid rules
- Is aware of advocacy referrals to assist clients

# Apply for All Available Programs

- SSI, Medicaid, Medicare
- State and local programs
- Programs sponsored by Local charitable organizations
- Community foundations



# Helpful Resources

- Medicare / Medicaid: [www.medicare.gov](http://www.medicare.gov)
- Centers for Medicare & Medicaid Services: [www.cms.gov](http://www.cms.gov)
- National Academy Elder Law Attorneys: [www.naela.org](http://www.naela.org)
- Special Needs Alliance: [www.specialneedsalliance.com](http://www.specialneedsalliance.com)
- ABLE National Resource Center: [www.ablenrc.org](http://www.ablenrc.org)
- Social Security: [www.socialsecurity.gov](http://www.socialsecurity.gov) or [www.ssa.gov](http://www.ssa.gov)

# Helpful Resources

- Protected Tomorrows Charities (formerly The Special Needs Network): [www.tsnn.org](http://www.tsnn.org)
- National Institutes of Health: [www.nih.gov](http://www.nih.gov)
- National Information Center for Children and Youth with Disabilities, Center for Parent Information and Resources (CPIR): [www.nichcy.org](http://www.nichcy.org)
- National Academy of Elder Law Attorneys: [www.naela.org](http://www.naela.org)
- Special Needs Alliance: [www.specialneedsalliance.org](http://www.specialneedsalliance.org)

# Keep the Big Picture in Mind

- Special needs planning is only one aspect of an overall estate plan
- Plan for your other children
- Fund the special needs trust
- Designate Successor Guardians



# What About Caregivers' Lifetime Care Needs?

- Life Insurance – protect surviving caregiver(s)
- Disability Insurance<sup>1</sup> – protects the caregiver's *income*
- Continuing Care planning options – get educated!

*How are you currently addressing these risks?*

<sup>1</sup> Products available through one or more carriers not affiliated with New York Life Insurance Company, dependent on carrier authorization and product availability in your state or locality.

