

Planning for Individuals with Special Needs:

How to Care and Protect Your Child's Financial and Legal Future

Presentation to:

**Parents and Families of CAPE Resources Center
September 29, 2021**

Our Discussion Today

- Introduction
- Reasons to Plan
- Estate Planning & Government Benefits
- Use of Trusts
- Special Needs Planning
- Protection Planning
- Managing & Investing for the Future
- What You Need to Know
- Other Considerations
- Q & A Segment

Profile: Who We Are

Lori Wolf, Esq.

- Member of the firm's Tax, Trust and Estates Department.
- Counsel individuals, families and business owners in all aspects of Tax, Trust and Estate Planning and Business Succession Planning.
- Emphasis on wills, trusts and sophisticated tax planning techniques and corporate planning involving closely held businesses.
- Focus on planning for families which have children with special needs and elder care planning.
- Active member of the Women President's Organization.
- Earned a B.A. from Washington University in St. Louis, a J.D. from Washington University in St. Louis
- Masters in Tax Law (L.L.M.) from New York University School of Law.

Profile: Who We Are

Richard L. Reda, LUTCF

- Agency Managing Director, Mass Mutual
- Insurance and Financial Advisor Since 1992
- Member of NAIFA & SFP
- Provides planning advice to Individuals, Professionals & Business Owners and their Families

Profile: Who We Are

James J. Di Gesu, CPA, PFS, MBA

- CPA/Financial Planner and Wealth Advisor for over 35 years
- Sr. Wealth Advisor at ***Belpointe Wealth Management***
- Clients include professionals, executives, retirees, professionals, business owners and their families
- Serves families with special needs children, ***Advisors for Angels***
- Sr. Vice President of *Wealth Health*
- VP, Private Wealth Management, *Bank of New York Mellon*
- Sr. Tax Manager with *KPMG* and *Deloitte & Touche*
- Member of AICPA, NJSCPA, CIA NJ, NJSO
- Graduate of Seton Hall & Fairleigh Dickinson Universities



My Daughters: Andrea & Michela



Special Needs Families in America Today

US Census Bureau Report

- Of 72.3 million families in Census, nearly 2 in 7 reported at least one member with a disability
- Of 20.9 million families reporting at least one member with disability, 5.5% of families have both adults and children
- 1 in 26 American families reported raising children with a disability
- 1 in 9 children under the age 18 receives special education services
- Nearly 2.8 million families or 1.3% reported raising two or more children with a disability



Special Needs Families in America Today

Other Statistics

- Nearly 80 million Americans cope with some form of disability.
- More than 41 million American or 15% of the population age 5 or older have some form of disability.
- Approx. 3 million children or 6.4% ages 5 to 15 have some form of disability
- Over 20% of Americans ages 6 to 16 suffer from some of physical, mental or emotional impairment.

Reasons to Create a Plan

- Increasing Population with Disabilities
- Increasing Demands for Services
- Increasing Life Expectancy
- Increasing Costs of Care
- Shrinking **GO**vernment **RE**sources



Reasons to Create a Plan

Lack of Planning by Special Needs Families

Alarming Statistics

- 69% are worried about providing lifetime care for their child
- 49% have not identified a Guardian
- 72% have not selected a Trustee
- 84% have not written a Letter of Intent
- 88% have not setup a Special Needs Trust
- 50% with life insurance lack confidence it is sufficient
- 63% have ***NO PLAN*** to meet expenses when they are gone!

Estate Planning & Government Benefits

Estate Plan Components

- Legal documents are cornerstones of estate planning and special needs planning
 - ✓ Wills
 - ✓ Trusts
 - ✓ Durable Power of Attorney
 - ✓ Health Care Proxy
 - ✓ Living Wills
 - ✓ Beneficiary Designations
- The documents alone will not deliver the necessary results
- Collaborate with a Special Needs Attorney

Government Benefits

Supplemental Security Income (SSI): Means tested assets, income

- ✓ Medicaid: Medical Insurance coverage if on SSI. Medical and means tested.
- ✓ Covers most group living arrangements.

Social Security Disability Insurance (SSDI): Non means tested

- ✓ Medicare: Medical Insurance coverage
- ✓ Does not cover living arrangements

Disabled Adult Child Social Security (DAC): Non-means tested

- ✓ Disability must occur prior to age 22.
- ✓ Eligible if parent receives SS, becomes disabled or dies.

Government Benefits

How Do I Provide Money or Assets to My Child and Avoid Loss of SSI and Medicaid?

- DO NOT leave the money to the child with special needs
- DO NOT leave the money to someone you trust to spend properly
- Leave the money to a SPECIAL NEEDS TRUST

Special Needs Trusts



Supplemental Benefit or Special Needs Trusts

1. Third Party Trust
2. Self-Settled Trust (d)(4)(A)
3. Pooled Trust (d)(4)(C)

Special Needs Trusts

Use of a Special Needs Trust for a Special Needs Child:

- Assets from SNT can supplement but can not replace government benefits
- Can be an *inter vivos* trust to receive gifts or inheritance from parents or others
- Parents need to communicate with family members to allocate gifts/bequests to SNT and not to child directly
- SNT can be revocable or irrevocable

Planning Point: State law can affect structure & requirements of SNT

Special Needs Trusts

Use of a Special Needs Trust for Your Child:

1. Funding of Special Needs Trust (“SNT”) at death.
2. Allocation to SNT before other children receive assets or divide assets equally between all children.
3. Cap amount to special needs child consider funding necessary amount with insurance.
4. The child with special needs can have no control or access to the trust funds.

Special Needs Trust

Use of a Special Needs Trust for a Special Needs Child

Assets of SNT's can ONLY be used to *Supplement* Gov't Benefits:

- Purchase of home
- Household and personal items
- Education, tuition, books, supplies, etc.
- Vacation, travel, entertainment
- Other

Assets of SNT's can NOT be used for the following:

- Can NOT give cash to the child
- Can NOT give cash to the family of the child

Assets of SNT's should be careful using funds for the following:

- Food, Clothing and Housing Expenses

Selecting Trustees

Who Should be a Trustee?

- Parent
- Corporate or other professional Trustee
- Successor Trustee

Responsibilities of a Trustee

- Invests and manages assets
- Distributes income and/or assets to the child
- Advocate for medical and financial entitlements
- Recordkeeping ability, knowledge of accounting and tax-planning
- Willingness to serve the duration of trust term

Attributes of a Trustee

- Acts in the best interest of the child
- Possesses integrity, impartiality
- Experience as a Trustee, has degree of financial savvy
- Has special sensitivity to a child with disabilities

Selecting Guardians

Parents Must Make The Decision:

- If < age 18 Designate Guardian in Will
- If child > age 18 Legal Guardian needs to be appointed once child becomes emancipated adult
- If not court will appoint guardian
- Consider use of PofA & Health Care Proxy for child if guardianship not appropriate
- Other Key Points:
 - ✓ Life-long Commitment of Caring
 - ✓ Guardian must be appointed by Court
 - ✓ Can be guardian of person, property or both
 - ✓ Protect and care for the child for life
 - ✓ Advocate for the child
 - ✓ Be accessible to the child and others



Special Needs Planning

Reasons for Planning

As a Parent What Keeps You Awake at Night?

Universally parents are concerned about their child's:

- Future Independence
- Financial Security, and;
- Quality of Life

Why is Special Needs Planning Important?

8 Obstacles to Planning:

1. Pressures of daily living
2. Health care issues
3. Educational system
4. Balancing life with multiple siblings
5. Complex financial matters
6. Managing limited time
7. Respite for parents
8. Uncertainty about future

What is Special Needs Planning?

It is a process to secure your family and your child's future financial security and quality of life.

1. Integrates traditional financial planning with uniqueness of your family.

PLUS

2. Integrates traditional legal planning with the necessary government benefits for your child.

= Comprehensive Special Needs Plan

Benefits of Planning

- Provide financial, physical security for your child as well as other family members
- Strategy in place for siblings and/or other future caregivers

Benefits of Creating the Plan

The Impact of Planning on Families

- People with a financial plan are more optimistic about their financial future than those without a plan.
- 95% of people who have a financial plan believe the benefits outweigh the costs.
- Positive financial behaviors like saving money and limiting debt can have a significant impact on people's financial outlook and sense of security.
- People with a financial plan are more likely to stay the course and exhibit disciplined financial behavior.

Special Needs Planning Process

9 Planning STEPS:

1. Address Family and Child's Needs
2. Identify Available Resources/Shortfall
3. Estimate Costs
4. Choose Knowledgeable Professionals
5. Make Decisions About the Future
6. Use Financial & Legal Planning to Meet Needs
7. Create Financial Plan
8. Execute Legal Plan
9. Monitor and Update Plan

Traditional vs. Special Needs Planning

Emergency Funds, Family Needs	Cash & Debt Management	Supplemental Expenses, Protection of Government Benefits
Wealth Distribution, Home Purchase, Investment Mgmt, College, Retirement	Personal Financial Planning & Investment Management	Gifts, Inheritances, Transitional Plans, Lifetime Residential Needs, Trust Mgmt.
Life, LT Disability, LT Care, Health, Home, Auto	Insurance & Risk Management	All Insurances, State Health Plans: Medicare and Medicaid
Wills, Trusts, DPOA's Health Care Proxy, Living Wills	Estate & Legal Planning	Selecting Guardians, Trustees, Caregivers, SNT, LOI, Titling of Assets

Planning Options

1. You can make no decisions or no plans, or;
2. You can make gifts or leave assets to your child, or;
3. You can disinherit your child, or;
4. You can distribute assets directly to other children or;
5. You can leave assets to a future caregiver, or;
6. You can and should establish a Special Needs Trust for your child

Protection Planning

Use of Life Insurance

Decisions, Decisions:

1. How much life insurance is necessary?
2. What type of life insurance is best for parents of a special needs child?
3. How should the life insurance be owned?
4. What are the biggest mistakes made related to life insurance by families with special needs child?

Types of Life Insurance

1. Term
2. Permanent or Whole Life
3. Universal
4. Variable
5. Survivorship or Second-to-Die

Commissioners Standard Ordinary (CSO)

Mortality Tables

❖ 1958 Age 90

❖ 1980 Age 100

❖ 2011 Age 121

❖ 2017 Age 121

Use of Life Insurance

Decision, Decisions - Again

1. How much insurance is necessary?
2. What is the cost and the affordability?
3. What type of life insurance is best? Permanent vs. Term
4. Should we buy multiple policies and types?
5. How should the life insurance be owned?
6. Can we use a trust or ILIT?
7. Can a child with special needs be named policy owner?
8. Who should be named Beneficiary Designation(s)?

Other Insurance Coverage

Do NOT Overlook Other Forms of Insurance

- Disability Insurance
- Health /Medical Insurance
- Property & Casualty Insurance
- Umbrella Insurance
- Long Term Care Insurance

Permanent vs. Term Life Insurance

- Due to needs being permanent, term insurance may not be best option
- Affordability of permanent insurance is often a concern
- Permanent insurance with cash surrender value may offset premium payments

Life Insurance in a Trust?

Avoiding Pitfalls and Common Mistakes

- Use of ILIT as logical owner
- Child with special needs should NEVER be named policy owner
- Proper Beneficiary Designation(s): SNT's
- 3-year “Look Back” Period
- Overpaying Term
- Insurance can meet the long-term needs of a special needs child but must be done with care!

Managing & Investing for Today & Tomorrow

Special Needs Trust

3 Questions You Must Ask Before Funding the SN Trust

Q1: How Much Money Is Necessary?

A: We must calculate the cost of care needed for your child's life.

Q2: Can Parents or Others Leave Assets to the SNT?

A: Yes. If estate assets are insufficient, the trust may NOT meet your child's lifetime expenses.

A: Must consider allocation of assets between your child with special needs and their siblings.

Q3: Can Life Insurance Proceeds Provide Cash to the Trust?

A: Yes and this can become a cash source to help meet your child's life-time needs.

Investment Management of Special Needs Trust

- Lifetime Needs Analysis
- Investment Objectives & Strategy
- Determine Investment Approach
- Prepare Asset Allocation
- Evaluate Investments
- Selection of Investment Managers
- Provide Reporting to Trustee/Family
- Monitor Investment Performance



Investment Management of Special Needs Trust

- Independent RIA
- Family Office
- Customized Approach
- In-House Money Managers
- Use SMA's, Mutual Funds, ETF's
- Traditional Active Management
- Tactical Active Management
- Alternative Investments
- Review Fees, Expenses, Transaction Costs



Questions to Consider

By planning today we can make for a different tomorrow

1. What kind of lifestyle is desired?
2. Where and with whom will your child live?
3. Who will make the financial decisions?
4. How will living expenses be met?
5. Who will make the health care decisions?
6. What type of care will be required?
7. What about the child's education?
8. Will a guardian or conservator be necessary?
9. What will the impact be on other family members?
10. What unforeseen challenges could arise?



What is the ABLE Act?

The FACTS

1. Achieving a Better Life Experience Act (ABLE) was passed December 2014
2. Created tax-exempt account to be used for the benefit of special needs individuals
3. Desire to make available to the disabled a fund while preserving their government benefits
4. ABLE accounts are similar to the 529 college plan accounts
5. Does NOT eliminate the need for Special Needs Trusts

The UNKNOWNNS

1. MUST be established in name of disabled person
2. Gives the person complete access to ABLE Plan
3. If child **unable** to exercise good judgment or fiscal responsibility not ideal
4. Special Needs Trust would be preferable
5. Estate Recovery Laws and Payback Provisions: If any money remains upon person's passing, NJ is entitled to be reimbursed for benefits paid out by NJ state on person's behalf, before any money can be distributed to heirs.

What is the ABLE Act?

The PROS

1. Funds can be used to pay Qualified Disability Expenses (QDE) includes education, housing, transportation, support services and more.
2. ABLE account supplements government benefits (SSI, Medicaid).
3. Interest earned is tax-free.

The CONS

1. Can ONLY deposit \$15,000/year (gift-tax exemption).
2. ONLY the first \$100,000 exempt for SSI eligibility purposes.
3. Eligible individuals whose disability occurred before reaching age 26.

Letter of Intent (LOI)

- The LOI is a vital document allows parents to communicate to caregivers their expressed wishes, hopes and dreams for the future of their special needs child.
- A guide for the people parents select to follow their wishes meeting the needs of their children.
 - Biographical, personal information, unique personality traits
 - Important people in child's life
 - Personal care, diet, habits & daily routines
 - Family details and information
 - Medical care, medical history and medical professionals
 - Education, schooling, social and recreational details
 - Parent's and child's financial information
 - List of financial advisors
 - Estate and legal documents
 - Current and future governmental benefits

Thank You for Your Time!

Please Contact Us to Schedule Your FREE Consultation:

Contact Information:

James J. Di Gesu, CPA, PFS, MBA

Belpointe Wealth Management

225 Glenville Road

Greenwich, CT 06831

Tel. 203-742-0557

Cel. 201-660-0839

Cel. 201-414-4002

James.DiGesu@BelpointeWealth.com

Belpointe 

Thank You for Your Time!

Please Contact Us to Schedule Your FREE Consultation:

Contact Information:

Richard L. Reda, LUTCF
Agency Managing Director
Mass Mutual Metro New York
One Penn Plaza
Suite 2035
New York, NY 10119
Direct: 646-473-4104
Cell: 516-244-5424
RichardReda@financialguide.com



Thank You for Your Time!

Please Contact Us to Schedule Your FREE Consultation:

Contact Information:

Lori Wolf, Esq.
Cole Schotz
Court Plaza North
25 Main Street
Hackensack, NJ 07601
TEL: 201-525-6291
loriwolf@coleschotz.com