

# Special Needs Planning: Financial & Estate Considerations



Lynda Kommel-Browne  
CFA®, CDEFA®, ChSNC®

# My Family's Story

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**Harrison (20), Sevie (25), Lynda, David, Wynston (19),  
Anelise (27) and B.K. (27)**

(with Gibbs the Autism Service Dog, and Noodles the Family Mascot)

## Specialized Professionals: CFAs, CDFAs and ChSNCs

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### CFA

**Chartered Financial Analysts** are highly skilled in investment analysis and portfolio management. The certification, which is held by elite investment managers spanning wealth management, investment banking, and hedge funds, signifies high level competency in areas such as ethics, economics, statistics, and wealth planning.



Credit: CFA Institute

## Specialized Professionals : CFAs, CDFAs and ChSNCs

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### CDFA

#### **Certified Divorce Financial Analysts**

serve as a bridge to the client's accountant and lawyer, providing support to financial planning and legal decisions with holistic family consequences in view. CDFAs serve as a pivotal part of the divorce team, analyzing short and long term issues related to property division, taxes, pensions, insurance needs, and other crucial considerations. A CDFA works with their client to set objectives, create budgets, and meet financial goals based on the lifestyle choices they make for themselves and their children.



Credit: Institute for  
Divorce Financial Analysts

## Specialized Professionals : CFAs, CDFAs and ChSNCs

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### ChSNC

#### **Chartered Special Needs Consultants**

help parents and guardians plan for short-term and long-term considerations for children or elders with special needs. The role draws from the disciplines of law, psychology, and financial planning to address a wide range of issues spanning special education, savings programs, and healthcare considerations.

ChSNCs advise clients to qualify for educational supports, government benefits and tax benefits, while guiding clients retirement and estate planning to pursue targeted outcomes for families' next generations.



Credit: The American College of Financial Services

# Topics for Discussion

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## I) Disability Conversations

## II) Estate Planning

Letter of Intent, Life Care Plan, Will, Living Will, Advance Directives, Guardianship, Conservatorship, Supported Decision Making, & Power of Attorney

## III) Financial Planning

Special/Supplemental Needs Trusts, 1st and 3rd party, Funding options, ABLE Accounts, Government Benefits, Insurance, Key points to consider when investing an SNT and ABLE account, & Review beneficiaries on *all* accounts

## IV) Midlife Disabilities



<https://www.manasotabuds.org/national-down-syndrome-society/>



Virginia Lawyers Weekly

## Important Questions to Ask

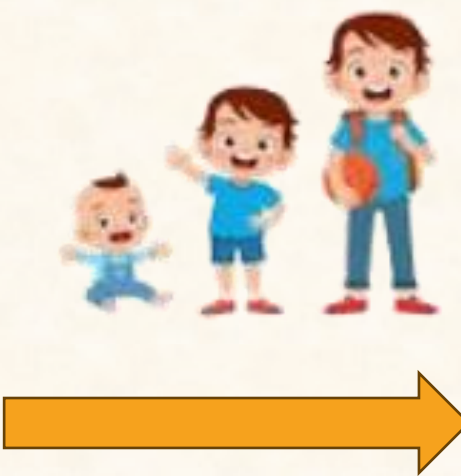
*\* Is there someone in your family who will not be able to be financially independent? \**

- ❖ Do you or your spouse have a vision on how your dependent with a disability will live after you are gone?
- ❖ Do you have a special or supplementary needs trust established to preserve government benefits?
- ❖ Will your dependent have adequate health insurance?
- ❖ Have you identified guardians, a conservator, or a trustee for your dependent?
- ❖ Have you make provisions to fund your trusts?
- ❖ Have you coordinated your special needs planning with other relatives?
- ❖ Do you have a complete understanding of Supplementary Security Income (SSI) or Social Security Disability Insurance (SSDI) government benefits?
- ❖ Have you done everything possible to protect your dependent's financial future?
- ❖ Do you have a letter of intent?

# Why is Disability Planning Necessary?

- ❖ Planning for two generations
- ❖ Assurance that families will not be disqualified from any state or federal aid available to them
- ❖ Legal and financial instruments needed for planning
- ❖ Provides ultimate peace of mind
  - *Necessity.*





**DIAGNOSES & ASSESSMENTS**

At key milestones we can help guide your path to validating diagnosis and pursue assessments

**Age 3-12**

**SCHOOLING**

Create a powerfully supportive IEP. Begin private school &/or higher education funding w/529 and ABLA tax-free savings accounts. Evaluate special needs trust (SNT) insurance-based funding.

**Age 13-15**

**INDEPENDENCE**

Maximize educational entitlements, explore vocations, enhance daily living skills. Pursue gov't respite, other entitlement benefits. Review strategic estate, life and financial plans. Update Letter of Intent.

**Age 18**

**ELIGIBILITY**

With legal adult status, manage assets for maximum government program eligibility. Plan guardianship and trustee arrangements, identifying primaries and successors. Review financial, and estate plans.

**Age 22**

**END OF SCHOOLING**

Formal end of IDEA-powered schooling and many supports. Work and residential arrangements loom. Review financial & estate plans and consider public & private funding options.

**Age 26**

**END OF PARENT'S HEALTH COVERAGE**

Private purchase of health care or formal qualification for government entitlements is now essential.

**PARENTS' RETIREMENT**

Possible lifestyle changes or concessions re: travel or location to care for adult child. Financial solutions like SNT needs trust are available for funding

**The Strategic Estate Plan of needs**

Two components: Legal documents and strategic life plan both kick-in. Gov't benefits, guardianship, family support, financial trusts and service supports are implemented. Wealth is distributed per plan.

**Parents' Death**



## The Dimensions of Disability

Disability	Description	Stressors
<b>Mental Health</b>	Behavior, thought, and mood disorders such as depression, anxiety, and bipolar disorder. Peak onset in late teenage years.	Impulsivity, tantrums, and meltdowns can strain family dynamic. Unpredictably episodic although stress can trigger. Many don't recognize often diagnosable illness. <b>Increases likelihood of divorce even more than developmental disorders.</b>
<b>Physical Incapacity</b>	Conditions that affect ability to perform activities of daily living (ADLs) – including physical capabilities, mobility, and functional impairments such as blindness, cerebral palsy, and epilepsy.	<b>Introduces financial and emotional challenges</b> , as well as those to pursue added accommodations for a child's successful functioning. Children with physical disabilities may be otherwise developmentally healthy and pursue successful, largely independent careers.
<b>Developmental Needs</b>	Physical, language, and learning impairments such as down syndrome, autism, and intellectual disabilities. Children's needs are often less apparent at the surface.	<b>Parents may require additional supervisory and respite services as well as face behavioral, medical and financial demands.</b> Extended family members <i>may</i> show more understanding towards a family with a child with developmental disabilities than children with other disabilities.
<b>Cognitive Limitation</b>	Mental functioning limitations either congenital or associated with injury (e.g., traumatic brain / concussion) and older age incapacities such as dementia or Alzheimer's.	Parental self esteem may suffer, extended families are generally supportive in the immediate aftermath, but their understanding and patience withers.

# Estate Planning for Special Needs

ESTATE PLANNING  
FOR SPECIAL NEEDS

Credit: Oaktree Law

## Life Care Plan

*Letter of Intent on steroids*

Lays out long term medical, psychological, and rehabilitation needs throughout one's lifetime regarding costs and recommendations

Day to day details... example:  
*Takes 50ml of X at 8am every other day*

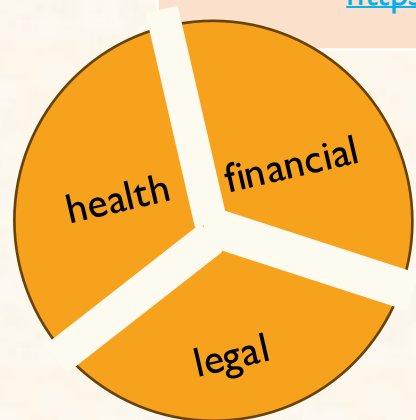
<https://www.youtube.com/watch?v=b60A-927WB0>

## Letter of Intent

Communicates concerns and wishes for the caregivers of your child/dependent following your death.

*"Vision for their best possible future."*

[2] "Life Care Planning," Special Needs Alliance, August 26, 2019,  
<https://www.specialneedsalliance.org/special-needs-101/life-care-planning/>.



**Consider having both. Think about what your child needs.**



# Possible Components of a Life Care Plan

## Keeping Track of Finances for Your Special Needs Child

Assets	Expenses
529 Plans	Medications
ABLE Plans	Housing
SSI (Supplemental Security Income)	Therapy
SSDI (Social Security Disability Insurance)	Leisure/Recreation/Entertainment
Investment Accounts	Education
Savings Accounts	Taxes
Roth Accounts / IRA Accounts	Groceries/Dining

# Letter of Intent

[Full Template for Letter of Intent](#)

[Example of a Letter of Intent](#)



Littman Krooks LLP






Special Needs Alliance

# Will, Living Will, & Advance Directives

Topics to discuss with your trust and estate or disability planning attorney.

- **Write your will.**
  - Update every 5 to 10 years
- **Have a living will**
- **Review beneficiaries**
  - Every couple years
- **Write Advance Directives** – Name who will have power over your child’s affairs upon your incapacitation. Make sure your wishes for your child are clear.
- **Do you need an SNT?**

Sample Advanced Directives Form  
(<https://www.ynhhs.org/patient-care/advance-directives-shared.aspx>)

MEDICAL RECORD NUMBER:	  
NAME:	
BIRTH DATE:	
DELIVERY NETWORK:	<b>Treatment Preferences and Living Will</b>

I am providing the information below to help my physicians and care team understand my care choices, particularly to help them understand my wishes relating to end-of-life care.

I already have a Living will or Advance Directive that I wish to be read in conjunction with this document.

I do not already have a Living Will or other Advance Directive, and would like Part 2 of this document to serve as my Living Will, and be read in conjunction with this document.

\*\*\*\*\*

**Part 1. Information About My Treatment Preferences**  
If I am no longer able to make my own health decisions, the information I have provided below outlines my goals and preferences for care at the end of life.

**Future health situations:**

- When you think about your health and health situations you may experience in the future, how do you feel?
  - Life is always worth living no matter what type of serious illness, disability, or pain I may be experiencing.
  - There may be some health situations that would make my life not worth living.
- How do you balance quality of life with medical care? If you had serious illness, what would be important to you?
  - I want medical treatments to try to live as long as possible. I would not want to stop treatment even if I were in pain, could not feed or care for myself, or needed machines to live.
  - I want to try treatments for a period of time, but I don't want to suffer. If after a period of time the treatments do not help or I am suffering, I want to stop.
  - I want to focus on my quality of life and being comfortable, even if it means having a shorter life.

**In the event of serious illness:**

- If I am terminally ill or so ill that I am unlikely to get better
  - I would not want to receive treatment to try to keep me alive
  - I would want to receive treatment to try to keep me alive
- If my doctors decide that I am likely to die within a short period of time, and life support treatment would only delay the moment of my death:
  - I would not want to receive treatment to try to keep me alive
  - I would want to receive treatment to try to keep me alive
- If my doctors decide that I am in a coma from which I am not expected to wake up or recover, and life support treatment will only delay the moment of my death:
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  - I would want to receive treatment to try to keep me alive

Credit: Yale New Haven Health

## II) Estate Planning

# GUARDIANSHIP, CONSERVATORSHIP, POWER OF ATTORNEY & SUPPORTED DECISION MAKING

# Power of Attorney

- A legal agreement created by a principal for the purpose of empowering one, the agent, in making financial decisions.
- Gives chosen person, agent, authority to act on one's behalf
- Agent must act accordingly to the person's wishes
- Can be cancelled at any time
- Findings of legal incompetence are *not* required
- Used to open bank accounts, make educational decisions, apply for benefits, decided where the person, principal, will live and sign leases.



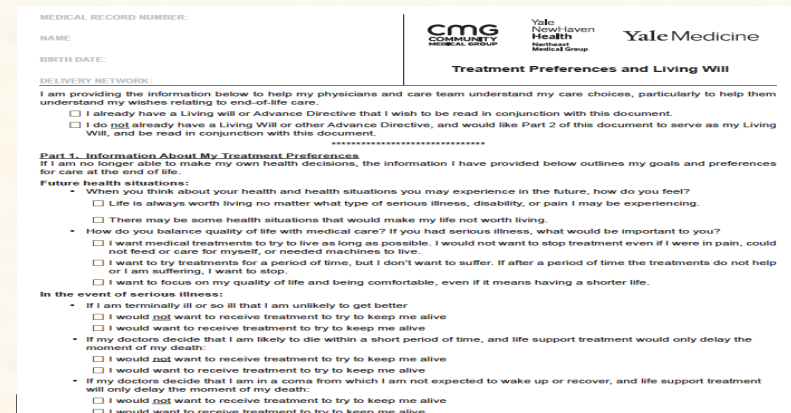
GETTY

## Requirements of Principal

- Comprehend the nature of the duties of a power of attorney
- Express wishes regarding financial transactions
  - Similar capacity as necessary for entering into a contract when purchasing an automobile

# Health Care Power of Attorney

- ❖ Created to allow another person to make decisions related to health care
- ❖ Creator is principal
  - Person to whom power is delegated is agent
- ❖ Principal must be:
  - At least 18 years old
  - Of sound mind
    - Statute says that, no finding of incompetence
- ❖ Takes effect upon finding of *incapacity* by
  - 2 physicians *or*
  - 1 physician and 1 psychologist
  - Who personally examine the principal
  - And sign a statement saying that the person has incapacity
- ❖ Old age, eccentricity, or physical disability, singly or together do



MEDICAL RECORD NUMBER: \_\_\_\_\_

NAME: \_\_\_\_\_

BIRTH DATE: \_\_\_\_\_

**DELIVERY NETWORKS**

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  - I would want to receive treatment to try to keep me alive

[Estate and Probate Legal Group](#)

# Supported Decision Making

An individual retains the freedom to make their own decisions, while receiving help and support if and when necessary.

A supporter assists in:

- ❖ Understanding the choices, responsibilities, and consequences of the individual's decisions
- ❖ Obtaining and comprehending relevant information for the individual's decisions
- ❖ Communication of the individual's decisions to the appropriate audience



# Supported Decision Making Autonomy

IS	DOES NOT
<ul style="list-style-type: none"> <li>• “A seat at the table”</li> <li>• An opportunity to learn and develop decision making skills</li> <li>• Recognition that we all need support to make decisions</li> </ul>	<ul style="list-style-type: none"> <li>• Institute decision-making authority</li> <li>• Establish determination of disability, incapacity, or incompetency</li> <li>• Supplant need for HIPAA or FERPA releases</li> <li>• Replace need for POAs</li> </ul>

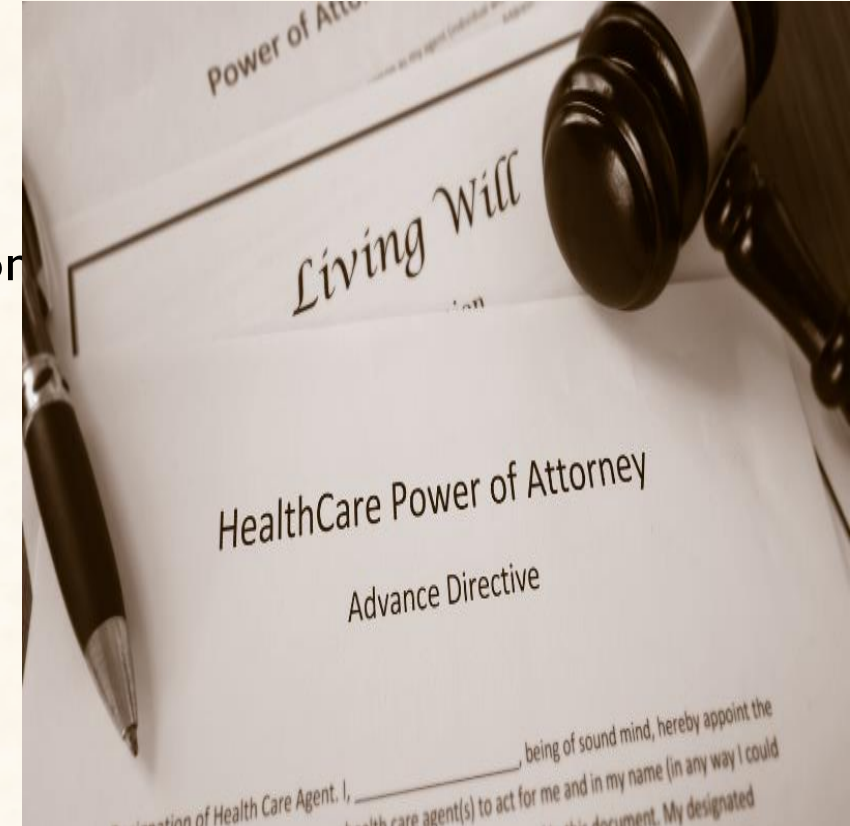


[https://us06web.zoom.us/rec/share/PrpSXfHbeWq3Man5LBYq6gfVhP2\\_KIzRLI3R4n8UUFISnR62oOsmX63WPeymmZR.sz5Pik0KGmj0lCK9](https://us06web.zoom.us/rec/share/PrpSXfHbeWq3Man5LBYq6gfVhP2_KIzRLI3R4n8UUFISnR62oOsmX63WPeymmZR.sz5Pik0KGmj0lCK9)



## Supported Decision Making Agreements

- ❖ Person with a "Functional Impairment"
  - Basically, anything that limits at least one major life activity
- ❖ 18 years or older
- ❖ Supporter can be anyone
  - Except for an individual with abuse or neglect charges/investigation against them
- ❖ Supporter cannot make decisions on behalf of or without the creator
- ❖ Any mandatory reporter still has a duty to report suspicious activity
- ❖ May *not* sign legal documents
- ❖ May *not* legally bind the individual in any way
- ❖ The existence of an SDM agreement does not preclude the individual from making independent decisions or from independently accessing protected information
- ❖ Cannot be used as evidence of incompetency for guardianship



[https://drive.google.com/file/d/1oBdI6QTsXpVoW9WxSdS\\_NwduTOWpnhKm/view](https://drive.google.com/file/d/1oBdI6QTsXpVoW9WxSdS_NwduTOWpnhKm/view)

- [Alabama Supported Decision-Making Statute \(2023\)](#)
- [Alaska Supported Decision-Making Statute \(2018\)](#)
- [Arizona Supported Decision-Making Statute \(2023\)](#)
- [California Supported Decision-Making Statute \(2022\)](#)
- [Colorado Supported Decision-Making Statute \(2021\)](#)
- [Delaware Supported Decision-Making Statute \(2015\)](#)
- [District of Columbia Supported Decision-Making Statute \(2018\)](#)
- [Illinois Supported Decision-Making Statute \(2021\)](#)
- [Indiana Supported Decision-Making Statute \(2019\)](#)
- [Louisiana Supported Decision-Making Statute \(2020\)](#)
- [Maryland Supported Decision-Making Statute \(2022\)](#)
- [Nevada Supported Decision-Making Statute \(2019\)](#)
- [New Hampshire Supported Decision-Making Statute \(2021\)](#)
- [New York Supported Decision-Making Statute \(2022\)](#)
- [North Dakota Supported Decision-Making Statute \(2019\)](#)
- [Rhode Island Supported Decision-Making Statute \(2019\)](#)
- [Texas Supported Decision-Making Statute \(2015\)](#)
- [Washington Supported Decision-Making Statute \(2020\)](#)
- [Wisconsin Supported Decision-Making Statute \(2018\)](#)

States with  
comprehensive  
legislation related to  
supported decision  
making agreements

*If it's not active in your state: do it anyway.  
Presume competence.*

# Conservator of Person

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# Guardianship of Person with a disability

\*Except, conservatorship pertains to an individual with an IQ of 70 or higher.

<https://www.kdhayeslaw.com/blog/guardianship-and-conservatorship-in-ct#:~:text=Conservatorship%20of%20Person%20is%20equivalent,individuals%20with%20a%20higher%20IQ.>

# Conservatorship

## Conservator of...

Person	Estate
<ul style="list-style-type: none"> <li>• Make medical decisions</li> <li>• Finding appropriate housing</li> <li>• Arrange for in-home support</li> <li>• Help access DVR or vocational coach</li> </ul>	<ul style="list-style-type: none"> <li>• Pay bills</li> <li>• Manage bank accounts, invest money</li> <li>• Sign a lease</li> <li>• Sign a cell phone contract</li> <li>• Apply for public benefits</li> </ul>



[https://us06web.zoom.us/rec/share/PrpSXfHbeWq3Man5LBYq6gfWhP2\\_KIzRLI3R4n8UUFISnR62oOsmX63WPeymmZR.sz5Pik0KGmj0ICK9](https://us06web.zoom.us/rec/share/PrpSXfHbeWq3Man5LBYq6gfWhP2_KIzRLI3R4n8UUFISnR62oOsmX63WPeymmZR.sz5Pik0KGmj0ICK9)

# Guardianship

## Guardianship Considerations:

It is important to think about who's going to make the decisions for the child with special needs when they reach age 18. Two types of guardianship parents must consider include:

### Guardianship of Person:

Guardian makes **personal, medical and educational** decisions for child, including treatment and behavioral therapy decisions. The guardian can also decide where the child lives. Divorced parents can be co-guardians of children.

### Guardianship of Estate:

Guardian can make **financial** decisions for child. Before the guardian uses or sells the child's assets, court approval is required.

What about a child that doesn't need a guardian but still needs a lot of parental support beyond 18 . Remember that parents do not have access to medical or educational records after their children turn 18 . Plan for this



Credit: Forbes Advisor

# Guardianship of Person

## Guardianship of Person (Continued):

Topics to discuss with your estate planning or family law attorney:

Many people tend to pick a guardian from their trusted adult friends or family, and there's a great comfort to that. **It is important to consider guardians who are considerably younger than the parents (likely to outlive them) and who can address all the *necessities* involved in raising the child.**

### Such necessities include:

- If the dependent is still a child will they be able to handle their school Individualized Education Plan (IEP)? Will the guardian live with or near the (then adult) child with disability?
- Will they support the child's social life? Will they take the child to compete in the Special Olympics, watch movies, eat at restaurants, attend events and concerts?
- Will they know the child's routines and be able to supervise and quality assure the fulfillment of responsibilities detailed in the Letter of Intent?
- Will the trustees, above all, be able to assure adequate supervision to avoid or detect abuse?



[Special Needs Answers](#)

# Guardianship of Estate

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## Guardianship of Estate (\$):

Guardians of Estate need to exercise sound judgement and possess a high level of financial competency. Their duties include:

- ***Maintaining inventory of assets, properties, and bank accounts***
- ***Filing annual reports detailing principal of estate and how it is being invested***
- ***Paying reasonable debts and obligations***
- ***Protecting and supervising management of assets.***

(<https://www.chesco.org/DocumentCenter/View/5063/Duties-of-the-Guardian-of-the-Estate?bidId=>)



Credit: Ladders

# Guardianship of Person

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## Additional Guardianship Considerations, Conservatorship:

Once a minor child has more than \$10,000 in assets, the *Guardian of Person* must also get an appointment as Guardianship of Estate from the court in order to manage the child's finances.

Alternatively, a Conservator must be appointed by the court to manage the estate (Conservator of Estate).

- Children with professionally documented IQ below 70 is characterized as having an intellectual disability (ID)
  - This level of ID warrants the legal requirement for a Guardianship of Person
- IQ of 70 or over warrants Conservatorship of Person



# Guardian Authority Limits

Guardians (generally) do NOT have the authority to...

- Limit visitors, friends, or phone calls
- Limit one's expression of religion
- Limit one's right to file grievances and/or consul with advocacy agencies
- Restrict one's personal choices: clothing, bedtime, haircuts, etc.



# Financial Planning for Special Needs

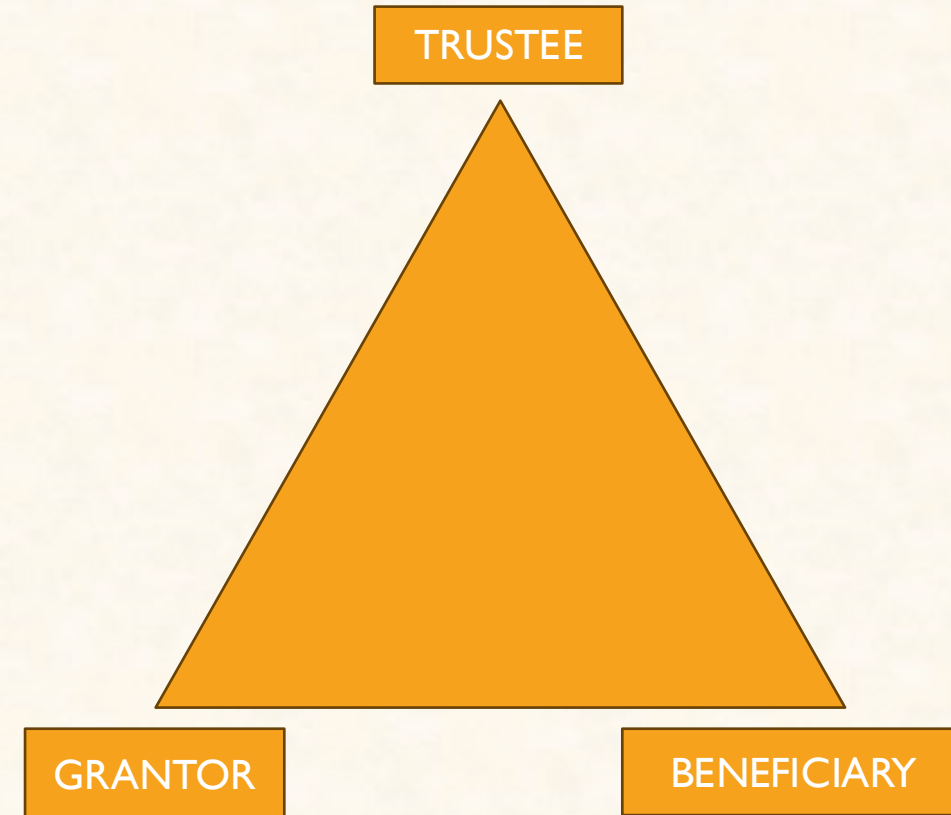
### III) *Financial Planning*



3  
|

# Basics of Special/Supplemental Needs Trusts

- ❖ Established by one or more grantors
- ❖ Administered by a Trustee
  - Individual or corporate
- ❖ For the benefit of an individual with disabilities
  - Beneficiary
- ❖ Intended to provide "supplemental care" and is *not* a basic support trust



### III) Financial Planning

## Third Party Special/Supplemental Needs Trusts

“other people’s money”

Created by donor who wants to gift money to individuals without interrupting public benefits

- Established by and funded with a third party’s assets
- Excluded from the definition of a trust as defined in a disability law and therefore not countable as a resource
  - Because not meant to spent on neither housing nor food
- Used frequently by parents/grandparents of a child with a disability
- Do *not* require court supervision or approval



<https://us06web.zoom.us/rec/share/wTmbY8HxoTBx6jSpQI2s4Zf3RHFiHFhmHS9hROObazsKNT4D8YTcrT5mPm78KFe3.LbbL7rWxt-rp9rP6>

### III) Financial Planning

# Creation of Third-Party Special/Supplemental Needs Trust

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Created using Last will and Testament, Living Trust, or Standalone SNT agreement.



SNT's Assets used for beneficiary and ultimately pass to family instead of reimbursing the State



Protects beneficiary's public benefit eligibility and provides funds for supplemental needs

<https://us06web.zoom.us/rec/share/wTmbY8HxoTBx6JSpQI2s4Zf3RHFihFhmHS9hROObazsKNT4D8YTcrT5mPm78KFe3.LbbL7rWxt-rp9rP6>

# First Party Special/Supplemental Needs Trusts

## “Self-Settled Trusts”

- Funded with the beneficiary’s own property
- Trustee obligated to file accounting with the state every three years
- State gets a payback provision → leftover funds go to the state to pay back Medicaid when the beneficiary of the trust dies



<https://us06web.zoom.us/rec/share/wTmbY8HxoTBx6JSpQI2s4Zf3RHFihHFhmHS9hROObazsKNT4D8YTcrT5mPm78KFe3.LbbL7rWxt-rp9rP6>

## Why would one start a self-settled trust?

Maybe the individual is in a car accident and receives settlement money...

...Or a relative passes away and leaves money directly to the individual

# Funding the Special/Supplemental Needs Trust

Funding SNT during one's lifetime	Funding SNT only upon one's death
<ul style="list-style-type: none"> <li>• Donor has more than enough money to meet personal needs</li> <li>• Donor wants comfort of knowing there will be a certain amount of money available for the beneficiary</li> <li>• Donor is implementing strategies to reduce their estate tax liability may wish to make periodic gifts to the SNT.</li> <li>• Protection from creditors</li> <li>• Money directly received by the child through inheritance and/or legal settlement that would otherwise disqualify them from benefits might be directed to an SNT with payback provisions.</li> </ul>	<ul style="list-style-type: none"> <li>• Once funded, money can <i>only</i> be used to meet the beneficiary's supplemental needs</li> <li>• Once funded, the trust becomes irrevocable</li> <li>• Trust requires a separate tax return</li> <li>• Taxes on income earned in the trust must be paid by the trust</li> <li>• Funding a special/supplemental needs trust while alive reduces flexibility</li> </ul>

"The Special Needs Planning Guide" by John W. Nadworny and Cynthia R. Haddad

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## Funding Options Upon Death

### Funding the SNT through Life Insurance

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Buy your life insurance - then put it in an irrevocable trust. This trust can be used to fund the Special/Supplemental Needs Trust.

Because:

- ❖ Outside of one's estate
- ❖ Cheaper
- ❖ Provides for individual with disabilities, and allows for business assets or other inappropriate assets for an SNT to be directed to other beneficiaries
- ❖ Useful tool for leaving larger share to individual with disabilities and smaller shares for other beneficiaries
- ❖ Tax reduction



ENT Credit Union

<https://www.specialneedsalliance.org/the-voice/funding-a-special-needs-trust-with-life-insurance-2/>

## Funding Options Upon Death

# Funding the SNT Through Passing on the IRA

Money left over from donor's IRA is passed on to the individual.

Normally, when IRA is passed on, the beneficiaries have 10 years to take the money out and pay taxes on it.

BUT, when directed to an SNT:

- Money can be taken out throughout the \*EBD's lifetime
  - o Because of the SECURE act, window is extended to individual's life expectancy
- Taxes are only paid on money taken out

*Note: IRA is outside of estate thus not subject to estate taxation until the individual passes.*

*\*Check that the SNT is the beneficiary and not the child\**



CPA Practice Advisor

\*eligible designated beneficiary

<https://www.plantemoran.com/explore-our-thinking/insight/2024/04/secure-act-and-special-needs-heirs>

# Beneficiary Designations



**CHECK ALL ACCOUNTS**



Any inheritance *must* go directly to the SNT.

Money over \*\$2,000 in previously opened accounts or any inheritance going directly to the individual can disqualify the individual from government benefits.

\*\$3000 for a married couple

[Social Security](#)

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### III) Financial Planning

# SNTs and Taxes

- ❖ “The IRS usually considers first-party trusts to be 'grantor trusts' – a classification that allows the reporting of all trust income, deductions, and credits to pass onto the beneficiary’s personal tax returns.”
- ❖ "On the other hand, a third-party SNT established by a friend or relative for a person with special needs may generate taxable income for the grantor of the trust, the beneficiary of the trust, the trust itself, or all three at once, depending on the circumstances."
- ❖ Income earned in a 3rd party trust is taxed at a significantly higher rate than personal income
  - "For 2026, personal income only reaches the highest tax rate (37%) when it exceeds \$640,600, whereas trust income is taxed at the highest tax rate (also 37%) when the trust income exceeds just \$16,000."
- ❖ Work with an accountant or financial advisor to understand
- ❖ Certain tax forms are required
  - Ex. 1041
- ❖ You might be eligible to deduct expenses from the trust
- ❖ The SNT might be able to pay trust and personal taxes



[True Link Financial](#)

# For what other deductions or credits could one be eligible?

## Child and Dependent Care Credit

- May be eligible to claim if you're paying care expenses for a qualifying individual to enable you to work or actively search for work
- Credit dependent on many factors but can be up to \$3,000 for an individual or \$6,000 for multiple qualifying individuals

## Medical Expense Deductions

- One may be able to deduct money spent on unreimbursed medical costs
  - Qualified medical expenses must be greater than 7.5% of one's AGI *and* one must choose to itemize returns
- Examples of qualifying expenses:
  - Insurance premiums, copays, and deductibles
  - Prescriptions drugs and insulin
  - Surgery and x-rays
  - Dentures, eyeglasses, hearing aids, wheelchairs, and other medical devices
  - Improvements to your home/vehicle to accommodate a disability
  - Transportation costs to/from medical care

## Qualified Disability Trust Exemption

- allowed a \$5,300 tax exemption in 2026

<https://www.truelinkfinancial.com/blog/family-caregivers-tax-season-what-you-need-to-know>

## SNT Planning Considerations

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### I) **Not smart decision making to mix 1st party funds with 3rd party funds.**

- a) 1st party SNTs are subject to Medicaid payback upon beneficiary's death
- b) 3rd party SNTs are not subject to these paybacks

### II) **SNTs have abilities that ABLE accounts lack**

- a) Can receive more than \$20,000 per year *plus* earned income limit
- b) Exceed \$100,000 and remain exempt for purposes of SSI
- c) Some trusts provide extra non-trust services to the beneficiary
- d) Pay for items that may not be "qualified disability expenses"
- e) Receive in-kind distributions (ex. stock, real estate, "inherited" IRA payable to the trust, etc.) vs. cash only

<https://www.youtube.com/watch?v=hE0mRv2cg5Q>

### III) Financial Planning



<https://www.manasotabuds.org/national-down-syndrome-society/>

## Achieving a Better Life Experience (ABLE) Plans

*(Available for Students and Family Members with disabilities)*

State or state-agency sponsored savings programs for individuals with disabilities.

Offer numerous tax and other advantages:

For those who qualify, opening an account is straightforward and fast.

- Earnings grow tax free.
- High maximum balances (varies by state plan) ranging from \$235,000 to \$529,000 + earnings
- Qualified withdrawals (disability-related expenses) are not subject to tax
- Some states offer income tax deductions or credit for account contributions
- Does not affect applications for financial aid
- Some states like Ohio call their ABLE accounts "STABLE" accounts
- ISS Market Intelligence estimates that only 1% of eligible Americans have an ABLE account
- For the first time, the 2020-2021 [FAFSA](#) mentioned ABLE accounts. The application "Help" sections of the following FAFSA questions, linked below, confirm that ABLE accounts are not considered an asset of the student or their parent in determining financial aid."
- (According to <https://www.able-now.com/resources/blog/impact-on-financial-aid/>)



### III) Financial Planning

## ABLE Physician Diagnosis Form: Sample (VA)

**ABLEnow.** Physician Diagnosis Form

Patient Name: \_\_\_\_\_  
Home Address: \_\_\_\_\_  
Date of Birth: \_\_\_\_\_

Patient is applying to open a tax-advantaged ABLEnow account. To establish eligibility to open and maintain an ABLEnow account, an individual must either be receiving Social Security Income (SSI) or Social Security Disability Income (SSDI) OR self-certify that they have a qualifying disability AND have a written diagnosis from a qualified physician. ABLEnow provides this form for applicants to provide to their physician to obtain the required written diagnosis.

---

**Provider:** Please complete this form and provide it to your patient for their records.\*

1. The attached medical diagnosis of the patient's impairment or impairments is based on my observation, testing and treatment of the patient.
2. The onset of this condition occurred before patient's twenty-sixth (26) birthday.
3. I am a medical doctor (MD) or doctor of osteopathy (OD), licensed to practice in the state in which I performed this diagnosis.

Provider Name (please print): \_\_\_\_\_  
Provider Title: \_\_\_\_\_  
Provider Signature: \_\_\_\_\_  
Date: \_\_\_\_\_

\*Completion of this form only establishes your patient's medical diagnosis and does not constitute your endorsement that the individual is eligible for an ABLE account.

(According to <https://www.able-now.com/resources/blog/impact-on-financial-aid/>)

## Who Qualifies for an ABE Account?

Beneficiary must have a disability with **onset before age of 46**

Update: Effective January 1, 2026, the ABE Age Adjustment Act is now in effect. The maximum age of onset for an individual's disability has increased from age 26 to 46.

[Social Security Matters](#)

“**PLUS** ONE OF THE FOLLOWING:

1. Eligible to Receive SSI or SSDI due to disability; or
2. Condition listed on SSA's "List of Compassionate Allowances Conditions"; or
3. Self-certification

WHAT IS SELF-CERTIFICATION?

1. Need diagnosis of a physical or mental impairment that causes “marked and severe functional limitations”
2. Condition has lasted or is expected to last for at least 1 year
3. Do not need to send in physician diagnosis, but must have one on hand”

- **Doug Jackson, Deputy Director - STABLE Accounts – Ohio State Treasurer**  
(<https://www.facebook.com/watch/live/?v=10155390358731688>)



## Who Qualifies for an ABLÉ Account?

**“Any disability that qualifies for SSI or SSDI or blindness that developed before the age of 26 is eligible for an ABLÉ account.** Some of the conditions recognized by the Social Security Administration that could qualify based on the level of severity include: blindness, Down Syndrome, hearing loss (deafness), epilepsy, autism/Asperger [syndrome].” (<https://ableforall.com/>)

These include disabilities related to:

- 1.00 Musculoskeletal System.
- 2.00 Special Senses and Speech.
- 3.00 Respiratory Disorders.
- 4.00 Cardiovascular System.
- 5.00 Digestive System.
- 6.00 Genitourinary Disorders.
- 7.00 Hematological Disorders.
- 8.00 Skin Disorders.
- 9.00 Endocrine Disorders.
- 10.00 Congenital Disorders That Affect Multiple Body Systems
- 11.00 Neurological Disorders.
- 12.00 Mental Disorders.
- 13.00 Cancer (Malignant Neoplastic Diseases).
- 14.00 Immune System Disorders.

*For more detailed information on disability criteria please go to:*  
[https://www.ssa.gov/OP\\_Home/cfr20/404/404-app-p01.htm](https://www.ssa.gov/OP_Home/cfr20/404/404-app-p01.htm)



## Who Qualifies for an ABLÉ Account?

### Qualifying disabilities listed by Fidelity's ABLÉ Eligibility Recertification Form:

**Developmental Disorders[:]** Developmental delay, Autism spectrum, and Asperger's disorder, or learning disabilities.

**Intellectual Disability[:]** Mild, moderate, or severe intellectual disabilities.

**Psychiatric Disorders[:]** Schizophrenia, anorexia nervosa, or bipolar, major depressive, post-traumatic stress, or attention-deficit/hyperactivity disorder.

**Nervous Disorders[:]** Blindness, deafness, congenital cataracts, severe hearing loss, cerebral palsy, muscular dystrophy, spina bifida, juvenile-onset Huntington's disease, or multiple sclerosis.

**Congenital Anomalies[:]** Chromosomal abnormalities, which include Down, Edwards, and Fragile X syndromes, Osteogenesis Imperfecta, Xeroderma Pigmentosum, or spinal muscular dystrophy.

**Respiratory Disorders[:]** Respiratory disorders including cystic fibrosis.

**Other[:]** Tetralogy of Fallot, hypoplastic left heart syndrome, juvenile-onset rheumatoid arthritis, hemophilia, and end-stage liver or sickle-cell diseases, or another disability not already listed.

([https://www.fidelity.com/bin-public/060\\_www\\_fidelity\\_com/documents/customer-service/able-eligibility-recertification.pdf](https://www.fidelity.com/bin-public/060_www_fidelity_com/documents/customer-service/able-eligibility-recertification.pdf))

## Achieving a Better Life Experience (ABLE) Plans

*(Available for Students and Family Members with disabilities)*

State or state-agency sponsored savings programs for individuals with disabilities.



**WARNING:** There is a Medicaid payback clause in play when receiving government benefits. If money is left in an ABLE account upon death of plan beneficiary, funds will be transferred to the state to compensate for any Medicaid expenses incurred by the government for their care.

- ABLE Accounts are comparable to First Party Disability Trusts in having payback provisions. If not used for qualifying medical or disability expense there is taxation and a 10% penalty.
- Third Party Disability (Special Needs) Trusts provide greater long-term planning options and control of assets upon the beneficiary's death (no payback provision).

*Please consult your tax accountant for IRS Questions*

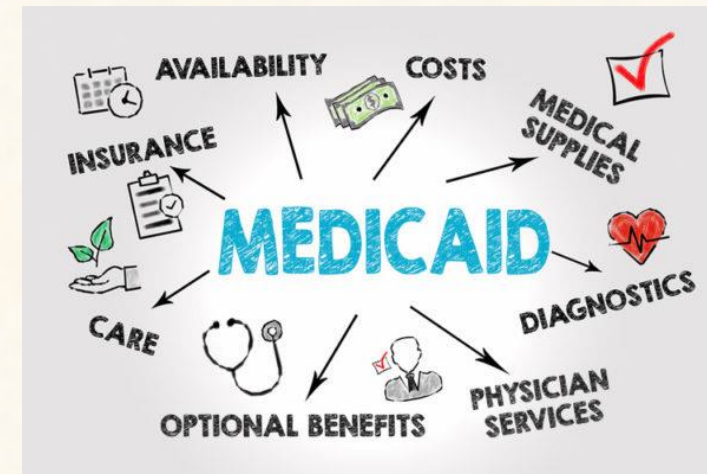
### III) Financial Planning

# ABLE accounts

Important consideration:

**If you're planning to get government benefits, outside the ABLÉ \$100,000 limit, most assets must be out of the child's name.**

To stay eligible for the full benefits of Medicaid, a person with disabilities must own no more than \$2,000, an ABLÉ account, a car, a prepaid funeral, and a house.



Credit: Home Care Delivered

(According to <https://www.able-now.com/resources/blog/impact-on-financial-aid/>)



# GOVERNMENT BENEFITS



5  
2

# What doesn't count towards resources?

assets that cannot inhibit one's acquisition of benefits

- ❖ One's home and the land it's on
- ❖ One vehicle if an individual or family member uses it for transportation
- ❖ Household goods
- ❖ Life insurance policies with combined face value \$1,500 or less
- ❖ Burial plots for individual or family member
- ❖ Burial funds \$1,500 and less for individual and individual's spouse's burial expenses
- ❖ Property on which individual or individual's spouse works
- ❖ Money or property set aside for Plan to Achieve Self-Support (PASS)
  - If disabled or blind
- ❖ \$100,000 or less in ABLE account



<https://www.ssa.gov/ssi/spotlights/spot-resources.htm#:~:text=To%20get%20SSI%2C%20your%20countable,you%20own%20do%20not%20count>

# Two Types of Government Assistance

Means Tested	Non Means Tested
<ul style="list-style-type: none"><li>❖ Social Security<ul style="list-style-type: none"><li>○ Supplemental Security Income ("SSI")</li></ul></li> <li>❖ Medicaid</li> <li>❖ Section 8 – Housing and Food Stamps</li></ul>	<ul style="list-style-type: none"><li>❖ Social Security Disability Income<ul style="list-style-type: none"><li>○ "SSDI"</li></ul></li> <li>❖ Medicare</li></ul>

# Health Insurance Options

---

## I) Private

- a) Most likely the best coverage
- b) Staying on parents' past age 26
  - Eligibility differ state to state  
[Forbes Advisor](#)

## II) Medicaid & Medicare



# Where can one stay on their parents' insurance past 26?

Eligibility Requirement	States
<p>Disabled dependents not capable of self-sustaining employment can stay on their parents' health insurance indefinitely. Note: eligibility is based on the state where the insurance is underwritten, not the state of residence.</p>	<p>California, Georgia, Idaho, Illinois, Indiana, Iowa, Massachusetts, Minnesota, Missouri, Nevada, New York, Ohio, Oregon, Rhode Island, South Carolina, South Dakota, Texas</p>
	<p>Idaho, Minnesota, Oregon, Rhode Island, Iowa</p>
<p>Source: National Conference of State Legislatures <a href="#">Forbes Advisor</a></p>	

### III) *Financial Planning*

## Medicaid

When pursuing government benefits or entitlement services...

- ❖ Keep in mind variances state to state
- ❖ Get help from a specialized company in your state
- ❖ Describe the individual's disabilities on their *worst day*



## Financial Considerations: Government Benefits

### Qualifying for Medicare

“Children over the age of 20 qualify for Medicare after receiving Social Security Disability Insurance (SSDI) benefits for at least two years (24 months). Your child may be able to receive SSDI, even with no work history, if they:

- **Developed a disability before age 22**
- **Have at least one parent who receives Social Security retirement benefits, and**
- **Are unmarried”**

(<https://www.medicareinteractive.org/get-answers/medicare-basics/medicare-eligibility-overview/medicare-eligibility-for-disabled-youths#:~:text=Children%20over%20the%20age%20of,a%20disability%20before%20age%2022>)



Credit: Mennonite Village

## Financial Considerations: Government Benefits

Supplemental Security Income	Social Security Disability Insurance
<b>Financing</b>	
Paid for through general tax reviews; independent of your earned income	Paid for with taxes from employers and employees; benefits depend on your income
<b>Health Benefits</b>	
Most beneficiaries are automatically eligible for Medicaid	Beneficiaries receive Medicare coverage automatically after two years
<b>Benefits Usable By</b>	
<ul style="list-style-type: none"> <li>• Individuals aged 65 or older</li> <li>• Adults who are disabled or blind</li> <li>• Children who are disabled or blind</li> </ul>	<ul style="list-style-type: none"> <li>• Blind or disabled workers</li> <li>• Beneficiary children</li> <li>• Widow(er)s</li> <li>• Adults disabled since childhood</li> </ul>
<b>Payments</b>	
Monthly payments have a federal maximum but this may be increased by state supplements	Amount is determined by Social Security earnings record of the beneficiary

Credit: Ritacco Disability Law

### III) Financial Planning

#### Government Benefits

##### Supplemental Security Income (SSI)

provides basic financial assistance to people with disabilities who have limited resources or income. In most states, beneficiaries of SSI automatically qualify for Medicaid upon after receiving SSI payments.



Credit: Partnerships for Action, Voices for Empowerment

##### Qualifying for SSI

“Your child must meet all of the following disability requirements to be considered medically eligible for SSI: • The child, who is not blind, must not be working or earning more than \$1,690 a month in 2026. A child who is blind must not be working or earning more than \$2,800 (this earnings amount usually changes every year). • The child must have a medical condition or a combination of conditions, that result in “marked and severe functional limitations.” This means that the condition(s) must very seriously limit the child’s activities. • The child’s condition(s) must have been disabling or be expected to be disabling for at least 12 months; or the condition(s) must be expected to result in death.”

(<https://www.ssa.gov/pubs/EN-05-10026.pdf>)

## Financial Considerations: Government Benefits

**Social Security Disability Insurance (SSDI)** provides basic financial assistance to people with disabilities who have a qualifying work history. Beneficiaries of SSDI automatically qualify for Medicare after 24-month initial waiting period. There is no waiting period for those with ALS.



Credit: Mathematica

### Qualifying for SSDI

**“The Social Security Disability Insurance (SSDI) program pays benefits to adults who have a disability that began before they became 22 years old. We consider this SSDI benefit as a “child’s” benefit because it’s paid on a parent’s Social Security earnings record.** For a disabled adult to become entitled to this “child” benefit, one of his or her parents must: • Be receiving Social Security retirement or disability benefits. • Have died and have worked enough to qualify for Social Security. **Children who were receiving benefits as a minor child on a parent’s Social Security record may be eligible to continue receiving benefits on that parent’s record upon reaching age 18 if they are disabled.** We make the disability determination using the disability rules for adults. SSDI disabled adult “child” benefits continue as long as the individual remains disabled. Marriage of the disabled adult “child” may affect eligibility for this benefit. Your child doesn’t need to have worked to get these benefits.”

(<https://www.ssa.gov/pubs/EN-05-10026.pdf>)

# Personal Assistance Services

Personal Assistant for an individual with disabilities to help with everyday activities

- *Not* medically based
- Family can control hours of working
- Help with dressing, bathing, cooking, etc.



Individual or family pays the assistant directly, reimbursed by the state

Major source of long term support for people with disabilities

"The Special Needs Planning Guide" by John W. Nadworny and Cynthia R. Haddad

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### III) *Financial Planning*

# Family Support

Increases capacity of the entire family.

- ❖ Respite care or personal assistance
- ❖ Vouchers to buy clothes, shoes, etc.
- ❖ Access to needed therapies
- ❖ Cash vouchers



"The Special Needs Planning Guide" by John W. Nadworny and Cynthia R. Haddad

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## Key Points to Consider When Investing an SNT and ABLE account

# The Benefits of Long-Term Investing

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### III) Financial Planning

## The Benefits of Long-Term Investing

Graphs from Macrotrends

S&P 500 (50-Year)



Over the last 50 years, the S&P 500 has provided annual returns of 7.84% given dividends are reinvested and adjusted for inflation ([S&P 500 Data](#))

S&P 500 (10-Year)



Over the last 10 years, the S&P 500 has provided annual returns of 11.3% given dividends are reinvested and adjusted for inflation ([S&P 500 Data](#))

S&P 500 (5-Year)



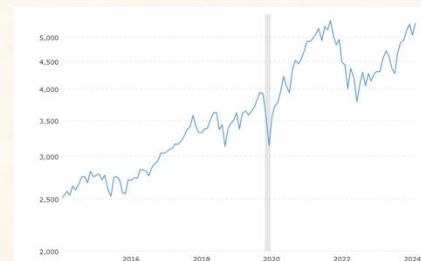
Over the last 5 years, the S&P 500 has provided annual returns of 8.9% given dividends are reinvested and adjusted for inflation ([S&P 500 Data](#))

NASDAQ (Since



Over the last ~47 years, the NASDAQ has provided annual returns of 9.1% given dividends are reinvested and adjusted for inflation ([DOYD](#))

NASDAQ (10-Year)



Over the last 10 years, the NASDAQ has provided annual returns of 15.8% given dividends are reinvested and adjusted for inflation ([DOYD](#))

NASDAQ (5-Year)



Over the last 5 years, the NASDAQ has provided annual returns of 10.0% given dividends are reinvested and adjusted for inflation ([DOYD](#))

All performance references is historical and is no guarantee of future results. All indices are unmanaged and may not be invested into directly.

## Investing if you don't have the luxury of the long term...



# The Benefits of Long-Term Investing



Macrotrends

# The Benefits of Long-Term Investing

Albert Einstein called compound interest “the 8<sup>th</sup> wonder of the world.”

Q: What is Compounding?

A: When investors receive interest payments from savings or receive dividends from stock investments, they can choose to either take that income OR reinvest it in their savings vehicle or stock investment. **When an investor reinvests their dividends or interest payments, they generate additional income or interest on interest.** This phenomenon is called **compound interest** or **compounding**.



Picture Credit: IRA Financial Group

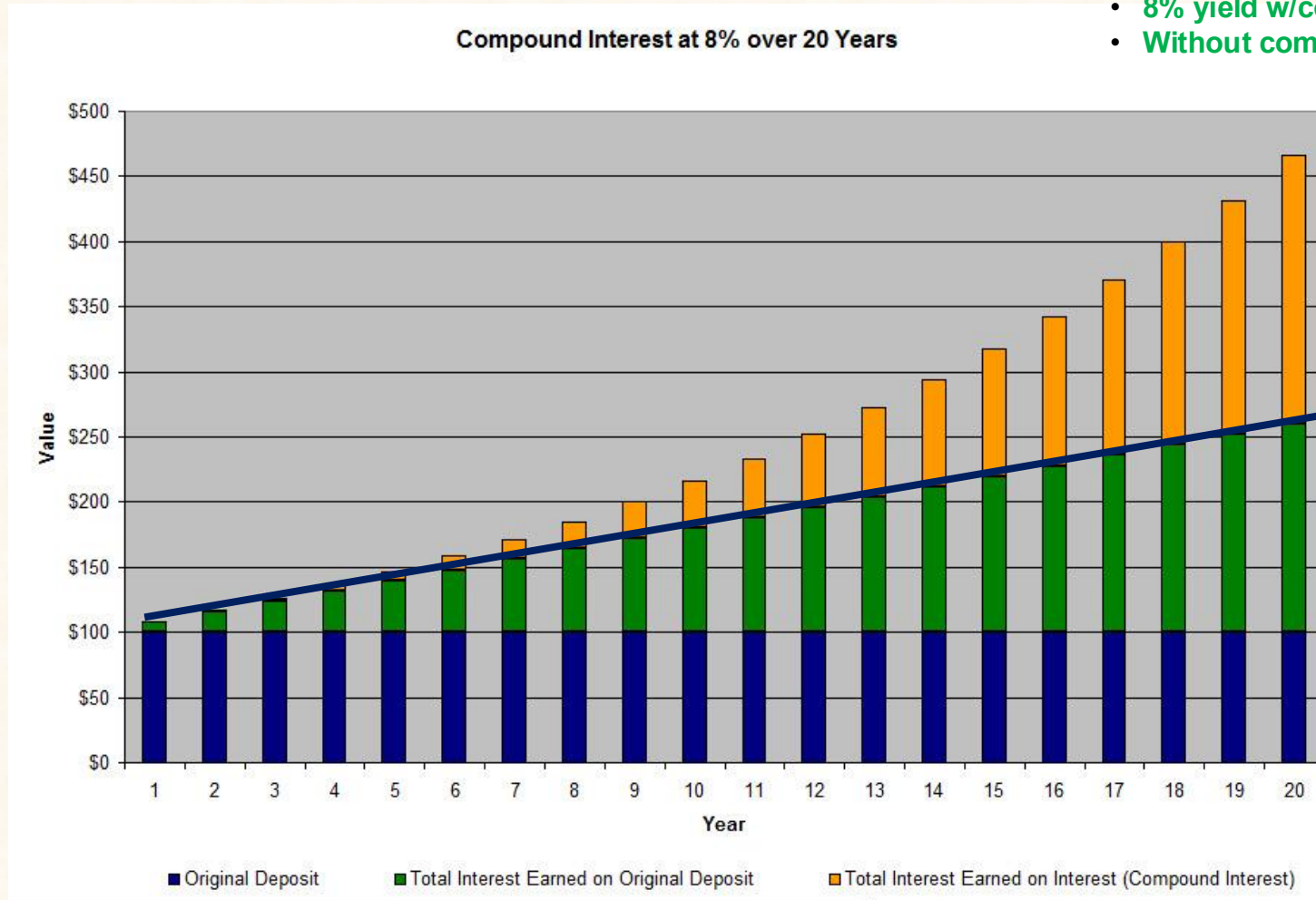
***Compounding begins to generate EXPONENTIAL GROWTH over the SPAN OF DECADES and is fundamental to generating long-term returns.***

# The Benefits of Long-Term Investing

## RETURNS: The COMPOUNDING Effect

Compound Interest at 8% over 20 Years

- Reinvested Interest /or Gains
- 8% yield w/compounding doubles returns ~every 9 years
- Without compounding it takes appx. 4 more yrs. to double



- Compounding Effect
- Straight-line Returns (8%)
- Principal = original investment ("basis")

Bottom Line: Tax free vehicles are wonderful bonus savings vehicles.

# The Benefits of Long-Term Investing

Growth in Taxable vs Tax-Free Accounts

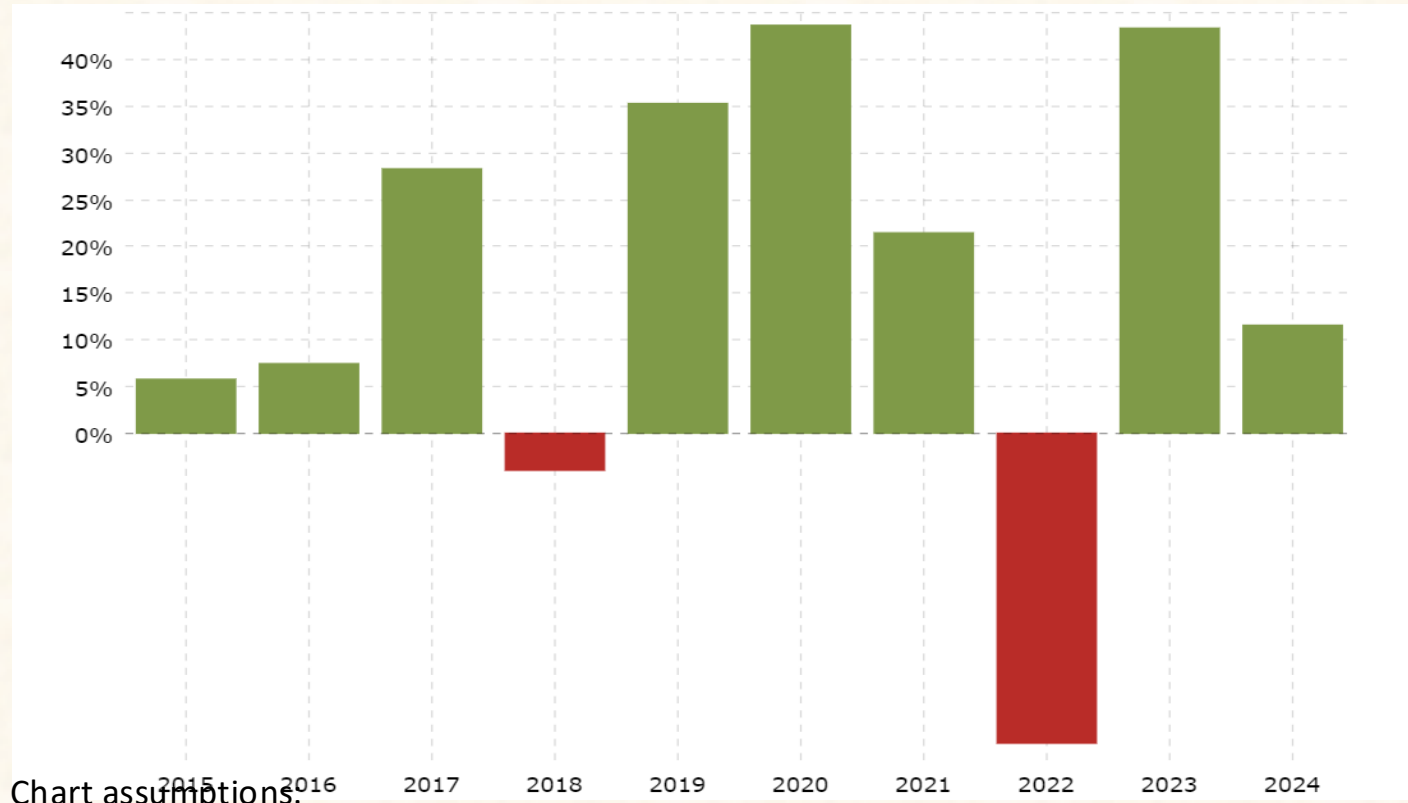


Chart assumptions:

Credit: Legg Mason, Thomson

37% Tax Rate

6% Growth Rate

# Common Mistakes

**Steer clear of these common mistakes parents of children with special needs may make when planning:**

- ❖ Have assets in the dependent's name
- ❖ Relying on your other children to take care of their sibling with special needs
- ❖ Disinherit your dependent with special needs
- ❖ Leave money to other children to support their sibling with special needs
- ❖ Failure to communicate your plan to family members
- ❖ Have 529s College Savings in your dependent's name
- ❖ Fail to fund trust properly
- ❖ Have the right kind of trust
- ❖ Die without a will



Malaysia Early Childhood Directory

# Midlife Disabilities

## IV) Midlife Disabilities

### Planning Ahead: Life Insurance, ABLÉ account, & First Party SNT

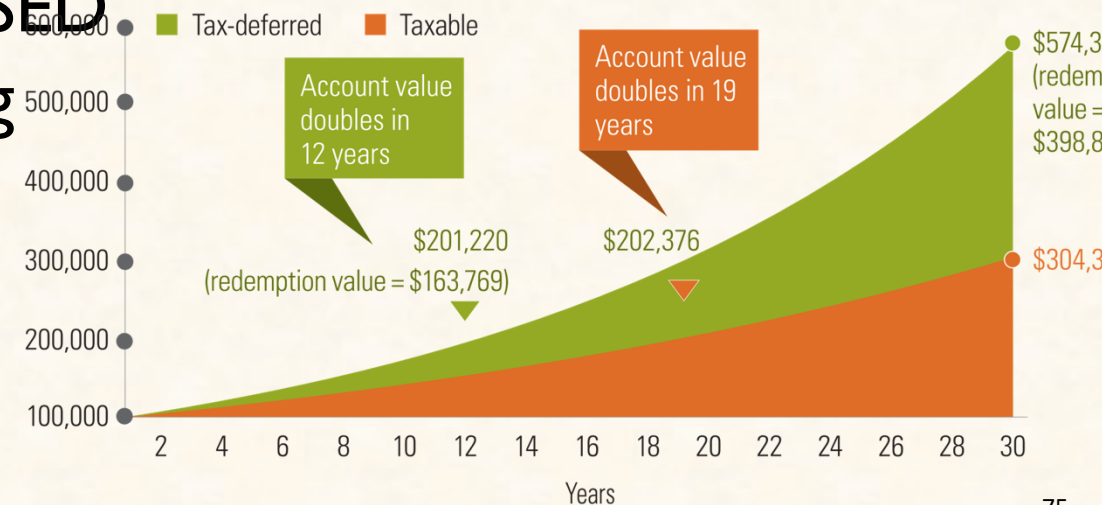
- ❖ If one becomes disabled from a medical or genetic condition midlife, the individual should consider taking out life insurance on their children to protect the child's insurability.
  - The insured would be your children. It does not matter if beneficiaries are not yet known.
- ❖ Looking seriously at your living will, health care proxies and advance directives
- ❖ If situation is warranted, consider setting up an SNT
- ❖ Starting in 2026, an individual can open an ABLÉ account if they become disabled before age 46 rather than 26.



# Have a conversation about advanced directives and living will

- ❖ Attorney's will *not* bring up unique conversation regarding advanced directives and living will
- ❖ Consider medical death
- ❖ Make a pact with a loved one regarding VSED
  - Voluntary Stopping Eating and Drinking

**Tax deferral can have a substantial impact on portfolio value**  
The growth of \$100,000 over 30 years (\$)



# CONCLUSION

Special needs planning is fluid and changing.  
Planning conversations need to be revisited every  
couple of years.  
Know your civil and disability rights.  
Build a team of supporters.  
**Presume competence.**

# More Resources

- ❖ [Read "Being Heumann: An Unrepentant Memoir of a Disability Rights Activist" by Judith Heumann](#)
- ❖ [Watch "Crip Camp: A Disability Revolution" directed by Nicole Newnham and James Lebrecht](#)
- ❖ [Special Needs Alliance](#)
- ❖ [ABLE National Resource Center](#)
- ❖ [Autism Empowerment / Spectrum Life Magazine](#)
- ❖ [Social Security Administration "Benefits for Children With Disabilities 2024"](#)
- ❖ [ENABLE - Special Needs Planning](#)



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