



The Essentials of Special Needs Planning

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Helping people with special needs and caregivers plan for the future they envision.

Agenda

- 1 Why plan?
- 2 Key lifetime planning phases
- 3 Integrated planning:
Four focus areas
- 4 Building a team
- 5 Resources
- 6 Key takeaways

There are different types of disabilities

Congenital disorder

- Down syndrome
- Autism
- Cerebral Palsy

Debilitating disease

- Multiple sclerosis
- Muscular dystrophy
- Mental health

Catastrophic event

- Stroke
- Heart attacks
- Service related

Aging population

- Alzheimer's
- Parkinson's disease
- Mobility



Increased life expectancy of those giving and receiving care can extend caregiving

Caregivers



- Family & friends
- Full or part-time
- Emotional and financial support

Who caregivers are

Anyone (immediate or extended family members, friends, spouses, partners, neighbors) who provide assistance to another who needs help as a result of a disability or special need.

***“There are only four kinds of people in the world:
Those who have been caregivers. Those who currently
are caregivers.
Those who will be caregivers, and those who will need caregivers.”***

-Rosalyn Carter



Physical effects of caregiving

83%

Use own sick time/leave/vacation to provide care

81%

Experience added stress/anxiety



70%

Have limited time to do things for self

72%

Have trouble sleeping

Findings throughout from an online survey of 510 HR Decision Makers respondents and an online survey of 1,815 employee respondents, both conducted by Voya Cares in partnership with Lieberman Research Worldwide (LRW) during the period of December 2, 2018 – January 14, 2019, unless otherwise noted.

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Financial effects of caregiving

Caregivers estimate that they spend an average of **\$825** per month on caregiving expenses

69%

Cut back on vacations or travel

59%

Dip into savings

61%

Delay a major purchase (i.e., car, furniture, home improvement)

69%

Cut back on spending for leisure activities

60%

Cut back on spending for other necessities (i.e., clothing, transportation, home utilities)

59%

Cut back on spending for basic home maintenance



Findings throughout from an online survey of 510 HR Decision Makers respondents and an online survey of 1,815 employee respondents, both conducted by Voya Cares in partnership with Lieberman Research Worldwide (LRW) during the period of December 2, 2018 – January 14, 2019, unless otherwise noted. *Monthly Caregiving costs captured as a self-reported metric

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Effects of caregiving on career

One of the most concerning revelations from the research was the fact that caregivers reported their responsibility caused them to:

56%

Cut back on work hours



31%

Leave one job for another



22%

Quit work entirely



Findings throughout from an online survey of 510 HR Decision Makers respondents and an online survey of 1,815 employee respondents, both conducted by Voya Cares in partnership with Lieberman Research Worldwide (LRW) during the period of December 2, 2018 – January 14, 2019, unless otherwise noted.

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Thinking ahead

- What type of future do you envision for you and your loved ones?
- How can you be sure your plans are carried out as intended?
- What resources are available, or will be required to make the vision come true?



Key lifetime planning phases

Key lifetime planning phases.

Foundation Birth – 3 years old

- Early Intervention
- Long term planning including Special Needs Trust and life insurance
- Individual Education Plan drawn up



Childhood and transitioning to adulthood 3 – 18 years old

- Individual Education Plan
- Education
- Transition planning
- Guardianship
- Workshops and adult education



Key lifetime planning phases (cont'd)

Young adulthood 18+

- Medical
- Housing
- Social life
- Education
- Employment



Parents' retirement

- Retirement savings
- Government benefits
- Beneficiary designations



Support beyond parents' lifetime

- Letter of Intent
- Special Needs Trust
- Will
- Guardianship





Integrated planning: Four focus areas

Key considerations for the special needs community

1

Family Assets and Planning

- Balancing needs of all family members
- Coordinating resources
- Caregiving planning (residential, social, etc.)

2

Employer Benefits

- Life, health and welfare
- Retirement plans
- Deferred compensation/stock

3

Government Benefits

- Means-tested benefits (Supplemental Security Income, Medicaid)
- Entitlements (Social Security Disability Insurance, Medicare)

4

Legal Planning*

- Wills, advanced medical directives
- Special needs trusts
- Titling – Ownership and beneficiaries



* Neither Voya © nor its affiliated companies or representatives provide tax or legal advice. Please consult a tax adviser or attorney before making a tax-related investment/insurance decision.

Family assets and planning

See the whole planning picture



Additional considerations for holistic planning



Planning

Need:

- Develop plan to enable a financially secure future
- Increased accumulation needs

Solutions:

- Financial Professional
- Educational material
- Life insurance
- Caregiving solutions
- Trusts/special needs trusts
- Self-settled trusts



Savings

Need:

- Retirement savings
- Healthcare savings
- Education savings
- Saving for Disability-related expenses

Solutions:

- Workplace Defined Contributions (DC) plans
- Individual Retirement Accounts (IRAs)
- 529 plans
- ABLÉ accounts
- Employer benefits
- Accumulation and investing accounts (e.g., money market and Investment accounts)



Investing

Need:

- Preserve and grow surplus income, savings, and lump sum inflows

Solutions:

- Equities
- Fixed Income
- Multi-asset strategies (target date funds)
- Retirement plans
- Investment management, assets for individual



Income Protection

Need:

- Predictable income and liquidity
- Stable and lower volatility assets

Solutions:

- Employer benefits
- Voluntary insurance solutions
- Retirement plans
- Individual life products
- Other insurance coverage: Disability, long term care (LTC)
- Annuity products
- Investment products, asset management

The Stephen Beck, Jr. ABLE Act (Achieving a better life experience)



ABLE Accounts:

- Assets in and distributions for qualified disability expenses will be disregarded or given special treatment in determining eligibility for most federal means-tested benefits
- State-established savings options providing more independence for people with disabilities and special needs
- Available in all states
- Eligible individuals include those who are on SSI or Medicaid or who meet the Social Security definition of disability and whose disability began prior to age 26
- Receive preferred federal tax treatment
- Enable savings for disability related expenses without jeopardizing eligibility for benefits
- May be subject to Medicaid payback
- Qualified disability assets and expenses will be disregarded in determining eligibility

ABLE accounts can be a great option, even for those not receiving public assistance. They can also be a tremendous complement to a special needs trust.

Visit Voyacares.com/ABLE to learn more.

Source: National Disability Institute (<http://www.realeconomicimpact.org/>)

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Employee benefits

Simple Strategies to help align your employee benefits with your special needs financial plan:

Carefully consider who you name a beneficiary

Take advantage of the employer match

Add layers of financial protection with life insurance

Plan for the unexpected with long-term disability insurance

Extend your support with the employee assistance program (EAP)

Save money today with health care spending accounts

Government benefits

Entitlement benefit vs. public assistance

Entitlement benefits

VS

Public assistance

- Social Security Retirement Income
- Family benefits
- Medicare
- Social Security Disability Insurance (SSDI)
- Survivor benefit

- Supplemental Security Income (SSI)
- Medicaid
- Public supports:
 - Supplemental Nutrition Assistance Program (SNAP)
 - Temporary Assistance for Needy Families (TANF)
 - Children’s Health Insurance Program (CHIP)

Note: Benefits may vary by state and jurisdiction.

Social security family benefits

**Retirement
or SSDI for
an individual**

Based on their own earnings record

**Benefits for
family
dependents**

Based on the earnings of the worker with a disability

Source: <https://www.ssa.gov/pubs/EN-05-10029.pdf>

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SSDI vs. SSI

Social Security Disability Insurance

- Payments come from the Social Security trust funds and are based on a person's earnings
- An insurance that workers earn by paying Social Security taxes on their wages
- Pays benefits to disabled individuals who are unable to work, regardless of their income and resources
- Benefits for workers and for adults disabled since childhood. Must meet insured status requirements

Supplemental Security Income

- Payments come from the general treasury fund, NOT the Social Security trust funds. SSI payments are not based on a person's earnings
- A needs-based public assistance program that does not require a person to have work history
- Pays disabled individuals who are unable to work AND have limited income and resources
- Benefits for children and adults in financial need. Must have limited income and limited resources

Entitlement benefits: Childhood disability benefit

If you experience a qualifying life event, your child with a disability may also receive a benefit after age 18, based on his or her parent's earning record and provided the child's disability occurred before age 22.

There are three life events:

- 1 Parent prematurely dies before retirement.
- 2 Parent becomes disabled.
- 3 Parent files for Social Security retirement.



Example:

Steve is an adult who became disabled before the age of 22 and is eligible to receive monthly income based on his parent's Social Security earnings record. He may receive up to 50% of his parent's benefit (amounts vary) and approximately 75% after the parent passes away. It is a separate benefit and does not decrease the amount paid to his parent.

Source: <https://www.ssa.gov>

Public assistance benefits: Medicaid

Medicaid – A Federal and State program

Essential public assistance program providing very broad and robust coverage for the financially needy and people with disabilities. Coverage varies by state but typically includes:



Health Care and
Prescription Drugs



Long Term Care
Facilities



Therapies and
Supports



At-Home Care

Public assistance benefits: Medicaid waivers



- A waiver is a program that can waive, or set aside, some of the strict eligibility requirements – including income guidelines, benefits and healthcare delivery options – required under federal Medicaid program regulations.
- A Home- and Community-Based Services waiver can provide extra services that make living at home possible. These services can include personal care, nursing, respite, adult day care, supported employment, home modifications, assistive technology and transportation.
- While waivers can differ substantially between states and counties in eligibility and services, an important advantage is that they can expand services to cover individuals who may be over the income requirements for traditional Medicaid.



Source: 1999-2018: <https://www.cincinnatichildrens.org/patients/child/special-needs/financial/coverage/waivers>

An overview of legal instruments



- Wills
- Advanced Medical Directives
- Durable Powers of Attorney
- Guardianship (person) and Conservatorship/Trustee (assets/property)
- Estate planning
- Trusts
- Special needs trusts (SNTs)



Three types of special needs trusts

First Party Trust



Assets such as inheritance, accident settlement or self settled

Third Party Trust



Funded by parents or family

Pooled Trust



Administered by non-profit organization

Planning a lifetime of care with a letter of intent

Vision for the future	<ul style="list-style-type: none">• Paint your vision of your loved one's future for successor caregivers
Daily Schedule and Recreation	<ul style="list-style-type: none">• Daily routines• Behavioral• Recreational activities
Food	<ul style="list-style-type: none">• Allergies• Favorite/least favorite foods
Environment	<ul style="list-style-type: none">• Residential• Social• Religious
Medical	<ul style="list-style-type: none">• Prescriptions• Providers• Records
Financial and Legal	<ul style="list-style-type: none">• Government Benefits• Professional Contacts, Location of Documents• Money management skills and goals

Building a team



- 1 Primary focus is on the person with special needs.
- 2 Develops a life care plan that enables that person to obtain the **BEST** quality of life in **ALL** stages of life.
- 3 A life care plan—one that covers an entire life—incorporates basic needs, goals and strategies.



Tools and resources

Resources

- Social Security Administration
- SSA.gov
- www.Specialneedsalliance.org
- Voya Cares

Voya Cares online resource center

Educational content

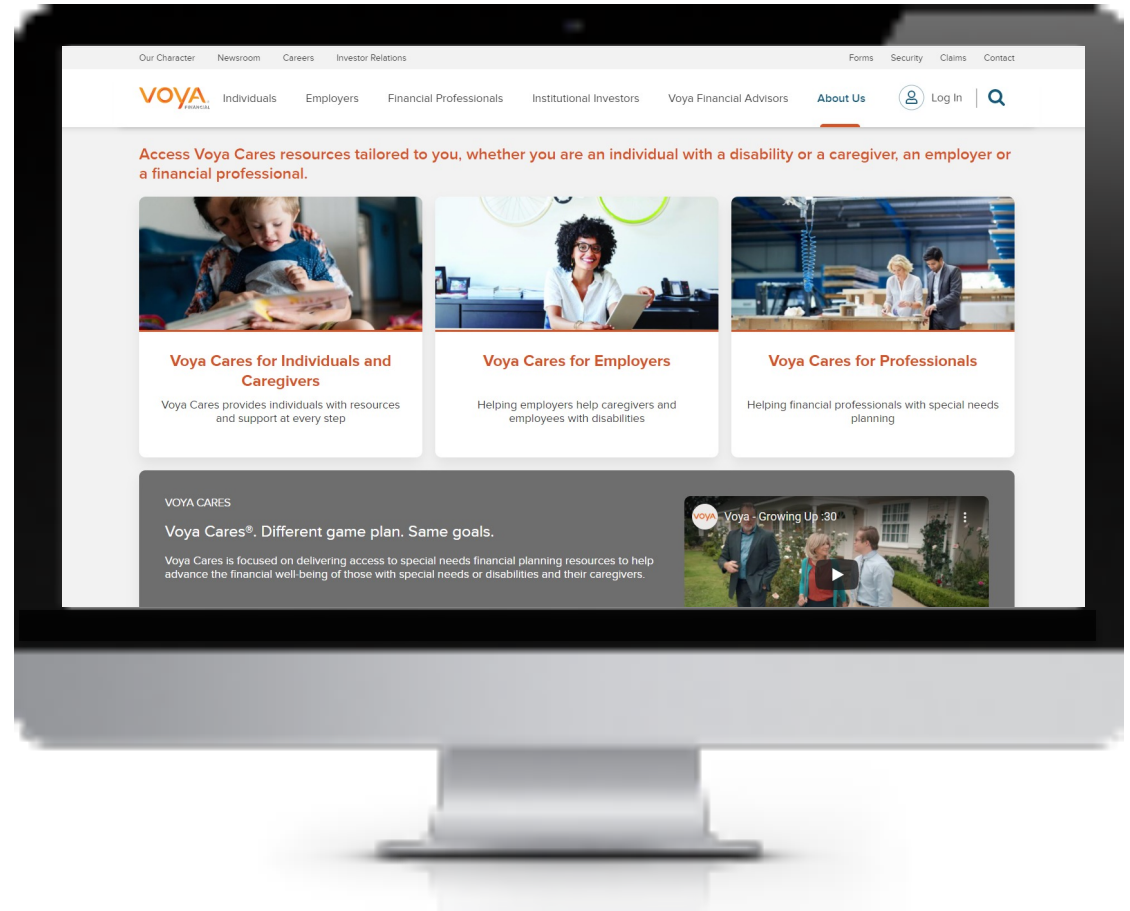
- Planning checklist
- Creating a letter of intent
- Understanding government benefits

Helpful articles

- Key considerations


Tools and resources

- Letter of Intent
- Advocacy groups
- Government benefits
- Financial and legal



Special needs planning checklist

Helps clients with special needs planning situations, especially if in beginning stages



Special needs planning checklist
Confidently checking all of the boxes means you are planning for a better future.

The journey of creating a lifetime of continuous care for your loved one may seem daunting at first, but getting started is less overwhelming when you're organized. Use the following checklist to begin planning the future your loved one with special needs deserves.

- Create a comprehensive Life Care Plan to ensure your loved one receives the long-term care they need.
- Create a Letter of Intent or "letter of instruction" to communicate information about your child as well as your vision of the future.
**Remember to update this document periodically as your loved one and vision of the future changes.*
- Make sure all family members and interested parties are informed of the Life Care Plan and Letter of Intent.
- Identify all financial resources available to create the future your loved one deserves, including government benefits, employer benefits and personal assets.
- Carefully review all medical health plan options and coverages, including Medicaid and Medicare.
- Choose a guardian, conservator and/or a trustee to oversee the care of your loved one when you're no longer able to.
- Utilize wills, special needs trusts and other legal instruments to craft a well-defined estate plan.
- Anticipate making changes to the Life Care Plan once the child reaches the age of 18 with consideration to:
 - Do you think your loved one will seek employment?
 - What types of housing accommodations do you anticipate?
 - Does your loved one have any special employment, housing, transportation, social and recreational interests?
 - Will they require any special transportation accommodations?

Whether you have one or all of the boxes checked, a specially trained professional can help you define or refine your plans and put them in action.

Visit voya.com/voyacares to learn more about special needs planning.

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- Create a holistic plan to ensure your loved one receives the long-term care they need.
- Create a Letter of Intent or "letter of instruction" to communicate information about your child as well as your vision of the future.
- Make sure all family members and interested parties are informed of the Life Care Plan and Letter of Intent.
- Identify all financial resources available to create the future your loved one deserves, including government benefits, employer benefits and personal assets.
- Carefully review all medical health plan options and coverages, including Medicaid and Medicare.
- Choose a guardian, conservator and/or a trustee to oversee the care of your loved one when you're no longer able to.
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- Anticipate making changes to the Life Care Plan once the child reaches the age of 18

Key takeaways from today's session

A plan allows you to be proactive, not reactive, to navigate life's traditional and special needs life events. It takes the overwhelming and breaks it into manageable pieces



Plan ahead –
Don't wait!



Four focus areas and
key planning phases



Maximize available
benefits



Understand the
necessary legal structures



Build your
team

Thank you!

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