

# Creating Financial Security for a Loved One With Special Needs

The Northwestern Mutual Life Insurance Company — Milwaukee, WI

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# Planning For Those With Disabilities

**82%**

of caregivers are concerned they do not have enough financial resources to last their disabled relative's lifetime

**77%**

of caregivers are concerned they won't be able to retire

**70%**

believe they will have to compromise their own retirement plans in order to provide for their dependent with specials needs

**60%**

of caregivers with life insurance have less than \$300,000 of coverage and fewer than half have the protection of whole life coverage. However, the lifetime cost of caring for a dependent with autism is between \$1.4 and \$2.4 million

**73%**

of caregivers don't have long term care insurance

**87%**

are concerned about what will happen to their child with disabilities when they (mom/dad) are no longer living

**59%**

of caregivers are concerned they do not have enough financial resources to last their disabled relative's lifetime

**67%**

of caregivers are concerned they won't be able to retire

**23%**

believe they will have to compromise their own retirement plans in order to provide for their dependent with specials needs

# Planning For Those With Disabilities



**Mikayla is  
15 years old  
& Avry is 9**

**Spontaneous mutation  
at conception led to  
Lissencephaly (smooth  
brain), Lennox Gestaut  
Syndrome, G-tube, non-  
verbal, non-ambulatory,  
ketogenic diet**

**Loves being social with  
friends, doing cross  
country, her service dog,  
Mickey Mouse, cuddles,  
toys that light up and blink.**

**20 years in financial  
services; 13 years  
specializing in special  
needs planning &  
being a mom**

**National practice with  
regular speaking  
engagements and  
training other advisors.**

# Mission



**Educate Strategic Partners**



**Guide Caregivers**



**Facilitate emotional conversations  
with key family members...**

...thus, we navigate the complexity of life planning for children/adults with special needs, and create a sustainable, high quality of life for everyone in the family.





**When it comes to  
your finances,  
what do you worry  
about most?**

# What We Hear Every Week...

**“We don’t  
know where to  
start...it’s too  
overwhelming.”**

**“We have it all  
taken care of.”**

**“We have a lot in  
place already, but no  
funding plan for our  
daughter’s special  
needs trust.”**

**“Wealthy families  
don’t need this  
planning.”**

# Keep In Mind



**It's Never Too Soon  
To Start Planning**



**You Don't Have To Do  
Everything at Once**



**You're Not Alone**

# Today's Agenda

1

**Building Your Team**

2

**Developing Your  
Special Needs Plan**

3

**Special Needs Trust**

4

**ABLE Plans**

**Let's get started!**





# MOST IMPORTANT!

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Families should never leave more than \$2,000 directly to their child with disabilities, even in a jointly held account.

## WHY?

To qualify for certain federal, state & local benefits, like Medicaid, SSI (or others), asset & income tests can apply.

# Why We're Different: Building Your Team

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## Identifying & Aligning Your Team



**Financial  
Professional**

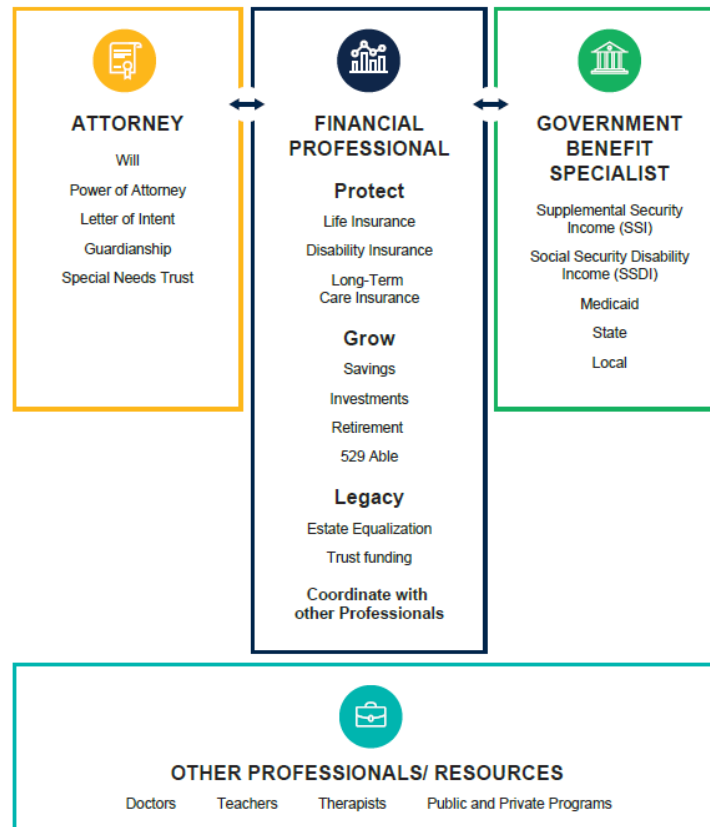


**Government  
Benefits Specialist**



**Attorney**  
(experienced in  
special needs)

# Special Planning For Special Families



# Developing Your Special Needs Plan

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Understand Where You Are and Where You Want To Go

## YOU:

- What are your savings and spending habits?
- What are your short-, medium- and long-term financial goals?
- What do you want for your future?



## YOUR LOVED ONES:

- What do you envision for your loved one's life?
- Where will they live?
- Who will provide day-to-day care?
- What social activities do you want them to be a part of?

# Developing Your Special Needs Plan

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Understand What Benefits Your Loved One is Eligible For:

- Social Security: Supplemental Security Income and Retirement Income
  - Medicaid: Health Care and Custodial Home Care
  - Vocational Services
  - Public School Services
  - Veterans' Benefits
- 

**Your government benefits specialist can make sure you're not leaving money on the table.**

# Will Your Loved One Qualify for Social Security Benefits?





# Supplemental Security Income

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## Child under age 18 with working parents



## Child age 18 or older with working parents



Must have little to no assets and a monthly income of \$900 or less to qualify for benefits at age 18

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**In 2024, the benefit amount could be up to \$914 a month.**

# Retirement Social Security

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## Retired Parent Taking Social Security and Child Considered Disabled Before Age 22

**Parents Taking  
Social Security**



**Parents'  
Work Histories**



**Child's Social  
Security Benefit**

Has no impact on the Social Security benefit the parents are receiving



**Remember:** Your loved one may qualify for benefits today or at some point in the future.

# Developing Your Special Needs Plan

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## A Government Benefits Specialist Can Help Estimate Future Costs

**Where  
You Live**



**The Care You  
Provide Now**



**Potential Annual  
Future Costs**

Government Benefits Specialist can help  
quantify costs and look for gaps



**Remember:** If your child outlives you, the care you provide now probably won't be a free service anymore.

# Third-Party Special Needs Trusts

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- These trusts help pay for supplemental needs that can enrich the life of your loved one.
- Anyone except your loved one with special needs can contribute.
- Government benefits generally should not be affected.



# Third-Party Special Needs Trusts



**1**

**Hire an estate planning or elder law attorney to draft your trust**

**2**

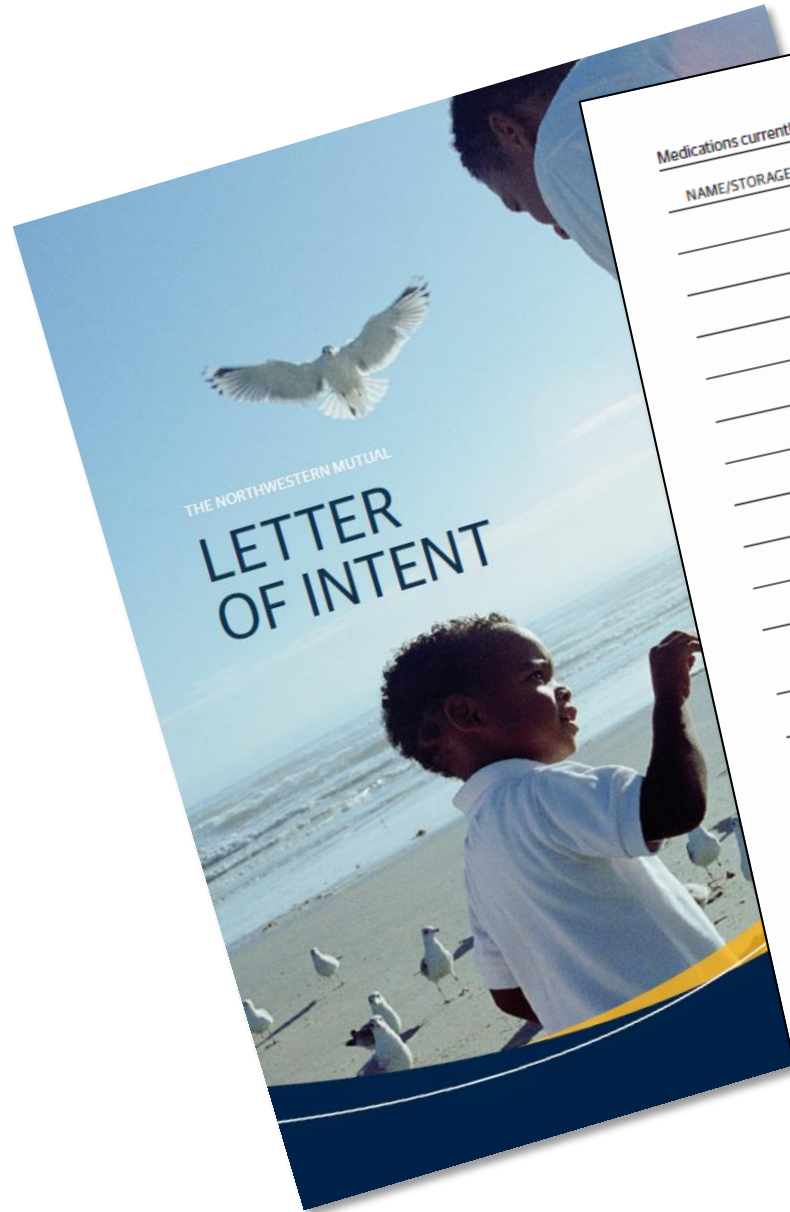
**Consider having a bank serve as trustee**

**3**

**Life insurance can fund a special needs trust**

**4**

**A trust can be set up, so the remaining assets pass to family members if the primary beneficiary passes away**



Medications currently being taken \_\_\_\_\_  
NAME/STORAGE LOCATION \_\_\_\_\_  
\_\_\_\_\_

**SLEEP HABITS**  
Bed time \_\_\_\_\_ Wake time \_\_\_\_\_ Favorite \_\_\_\_\_

**ACTIVITIES**  
Education \_\_\_\_\_  
Work \_\_\_\_\_  
Exercise \_\_\_\_\_  
Habits \_\_\_\_\_  
Hobbies \_\_\_\_\_  
Other interests \_\_\_\_\_  
Social/recreational/religious \_\_\_\_\_  
Favorite things (places to go) \_\_\_\_\_  
Dislikes \_\_\_\_\_  
Current daily schedule \_\_\_\_\_

**VALUES AND BELIEFS**  
Your hopes and dreams \_\_\_\_\_  
\_\_\_\_\_  
Behavioral \_\_\_\_\_  
Current \_\_\_\_\_  
Potential \_\_\_\_\_  
Other \_\_\_\_\_  
What problems \_\_\_\_\_

**MEDICAL INSURANCE**

PROVIDER	POLICY NO.	GROUP NO.	PLAN PARTICIPANT NAME	TYPE/LEVEL OF COVERAGE

**DAILY LIVING SKILLS AND ABILITIES**

LEVEL OF ASSISTANCE	NO ASSISTANCE	SOME ASSISTANCE - DESCRIBE	DEPENDENT - DESCRIBE
Bathing			
Dressing			
Toileting			
Sleep Routines			
Travel			
Cooking			
Housekeeping			
Bill Paying/Money Management			

Other limitations/comments \_\_\_\_\_  
\_\_\_\_\_

**NUTRITIONAL PROFILE**  
Food allergies/restrictions \_\_\_\_\_  
Favorite foods \_\_\_\_\_  
Size of food portions \_\_\_\_\_  
Eating or swallowing problems \_\_\_\_\_  
Outcome if restricted foods are consumed \_\_\_\_\_



# ABLE or 529A Plans

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**Public benefits often have asset limits of \$2,000.**

## **ABLE (ACHIEVING A BETTER LIFE EXPERIENCE) PLANS:**

- **May be created any time if disability onset prior to age 26**
- **Will not affect Medicaid eligibility no matter how large the account grows**
- **If account balance is \$100,000 or more, it will affect Supplemental Security Income eligibility**
- **Contributions are post-tax and are not tax deductible at the federal level (some states allow deductions)**
- **Contributions of \$18,000/yr allowed + \$14,590 from earnings**
- **Can roll 529C accounts into 529A plans**
- **Assets grow tax free and qualified distributions are tax free**

# ABLE or 529A Plans

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## Used for:



- **Education**
- **Housing**
- **Transportation**
- **Employment training**
- **Assistive technology**
- **Personal support**
- **Health care expenses**
- **Expenses that improve health, independence or quality of life**




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**Any money left in the plan at death must be used to reimburse the state for Medicaid support**

# Determining if an ABLÉ Plan Is Right for You

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1. Talk to your financial professional.
2. Visit [ablenrc.org](https://www.ablenrc.org) to learn more about your state's ABLÉ plans.



**ABLE** NATIONAL RESOURCE CENTER  
ACHIEVING A BETTER LIFE EXPERIENCE ACT



### Which state has the best program for you?

No matter which state you call home, you can open your ABLÉ account in any state with an active ABLÉ program.

[SELECT A STATE TO BEGIN →](#)

(Blue indicates active programs.)

You can also use our [TOOL THAT COMPARES STATE PROGRAMS](#).

**Don't Forget  
To Plan For  
Yourself, Too!**



# Planning for Your Financial Future



**Planning for your loved one with special needs is critical... but it's only part of your financial plan.**

- What do you want for your own future?



**Find a financial professional to help you:**

- Identify your goals
- Set priorities
- Create and execute a customized plan
- Keep your plan aligned with your changing life

# Choosing a Financial Professional

**1**

**Work with someone you trust**

**2**

**Choose someone who is experienced  
in planning for special needs**

**3**

**Make sure your financial professional with  
work with you over time as your needs change**

**4**

**Select a company that has strong history  
and maintains the highest financial  
strength ratings in the industry**



# RECAP



## ASSEMBLE YOUR TEAM

Financial Professional, Government Benefit Specialist and Attorney



## DEVELOP A SPECIAL NEEDS PLAN

- Understand your current situation
- Decide what you want for the future
- Get the benefits your loved one is eligible for
- Estimate future cost of care
- Establish and fund a special needs trust and/or ABLE plan



## DON'T FORGET TO PLAN FOR YOURSELF

**Schedule Your  
Free Consultation Today**  
**414-839-5905**

**Melissa Burback**

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# Thank You

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