

# CREATING A LIFE PLAN

for a Loved One With Special Needs 



# CAREGIVER STATS

\*Greenwald & Associates for the American College: Special Needs Caregiver Survey (2016)

# CAREGIVER STATS

82%

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

# CAREGIVER STATS



**77%**

are concerned they won't be able to retire.

# CAREGIVER STATS



**70%**

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

# CAREGIVER STATS



**60%**

of those with life insurance have less than \$300,000 of coverage and fewer than half have the protection of whole life coverage.

# CAREGIVER STATS

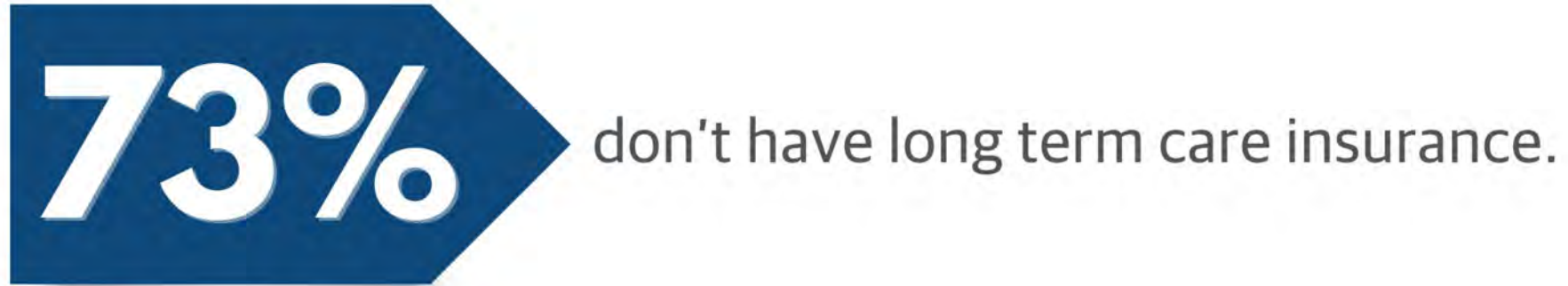


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The lifetime cost of caring for a dependent with autism is between \$1.4 and \$2.4 million.

# CAREGIVER STATS





# CAREGIVER STATS

87%

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

# CAREGIVER STATS

**59%**

have not written a Will addressing the special needs of their relative.

# CAREGIVER STATS



# CAREGIVER STATS

**23%**

of families have a formal financial plan for their dependent...

# CAREGIVER STATS

**37%**

...work with a financial advisor.

# MEET THE SEITZ FAMILY

- Hudsyn is 14 years old
- Birth Injury: Spastic Quad Cerebral Palsy, CVI, Structural Focal Epilepsy, G-tube dependent, non-verbal, non-mobile, etc.
- Loves story time, the color purple, K-State Wildcats, Enrique Iglesias, and anything that sparkles
- Damek is 12 years old
- Level 1 Autism and ADHD
- Loves Roblox, Formula 1 racing, computer programming and math



# YOUR TEAM



Director of Financial  
Planning

Financial Planning  
Specialist

Ashley

Jason

Anthony

# 32

years of combined experience  
in financial services

# 2013

our practice began

# 400+

families that we serve  
(and love!)

# 1

special needs book published

# KACY'S BOOK

From our firm's founder, Kacy Seitz, comes a bold and honest memoir. A relatable account of her family and their journey of navigating their newborn's brain injury, and ultimately, how they've learned to handle things.





# CREDENTIALS & AFFILIATIONS

Special needs planning is not a part of our story. **It's our whole story.**



Appointed by Kansas Governor Laura Kelly, Kacy serves on the Advisory Commission for Children with Special Health Care Needs.

Their mission is to consult with and advise the Kansas Secretary of Health and Environment on matters relating to children with special health care needs.



Kacy currently sits on the Kansas Council on Developmental Disabilities. This committee is responsible to carry out the provisions of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).



Individuals who have the designation of chartered special needs consultant (ChSNC) are the only financial advisors who have been specifically equipped and vetted to advise you on the financial and estate planning needs of special needs clients.



The Academy of Special Needs Planners consists of special needs planning professionals such as attorneys, financial planners and trust officers who provide the highest quality service and advice to persons with special needs and to their families.

# MISSION

How We Do It.

- ✓ Educate strategic partners.
- ✓ Guide caregivers.
- ✓ Facilitate emotional conversations with key family members...

# MISSION

How We Do It.

We approach this work with Grace, Integrity, and Compassion to allow financial independence for all.




**WHEN IT COMES TO YOUR  
FINANCES...**

**WHAT DO YOU WORRY  
ABOUT MOST?**

# WHAT WE HEAR EVERY WEEK...

# WHAT WE HEAR EVERY WEEK...



"We don't know where to start..  
it's too overwhelming."

# WHAT WE HEAR EVERY WEEK...

"We have a lot in place already,  
but no funding plan for our  
daughter's special needs trust."



# WHAT WE HEAR EVERY WEEK...



"We have it all taken care of."

# WHAT WE HEAR EVERY WEEK...

“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

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## 01 Building your team

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**01** Building your team

**02** Developing your special needs plan

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**03** Special Needs Trusts



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**04** ABLE Plans

# MOST IMPORTANT THING



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

# MOST IMPORTANT THING



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

# WHY WE'RE DIFFERENT:



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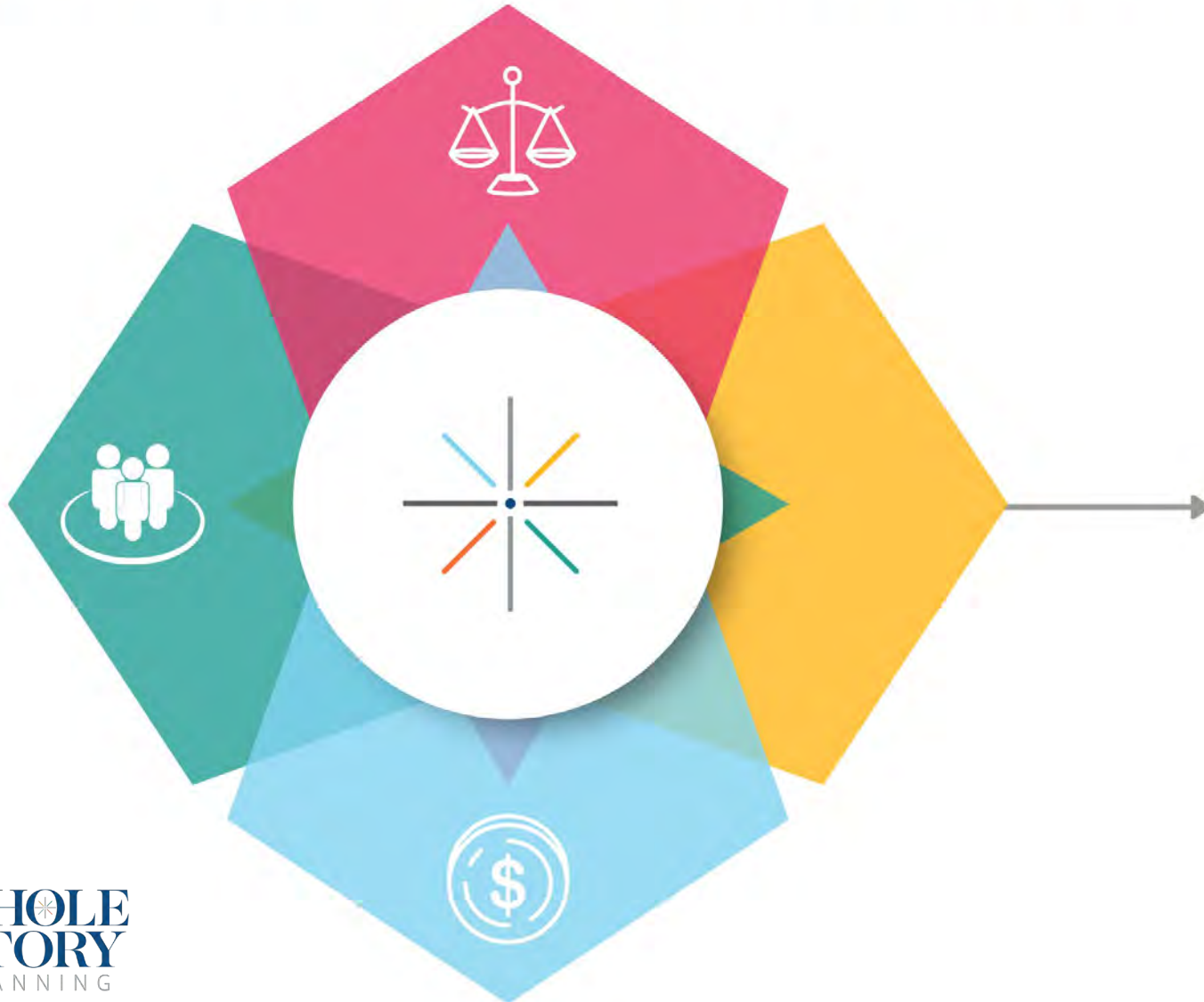
## FINANCIAL PROFESSIONAL

Life Insurance  
Disability Insurance  
Long-Term Care Insurance

Savings  
Investments  
Retirement  
529 ABLE

Estate Equalization  
Trust Funding

# WHY WE'RE DIFFERENT:



BENEFITS  
SPECIALIST

Supplemental Security  
Income (SSI)

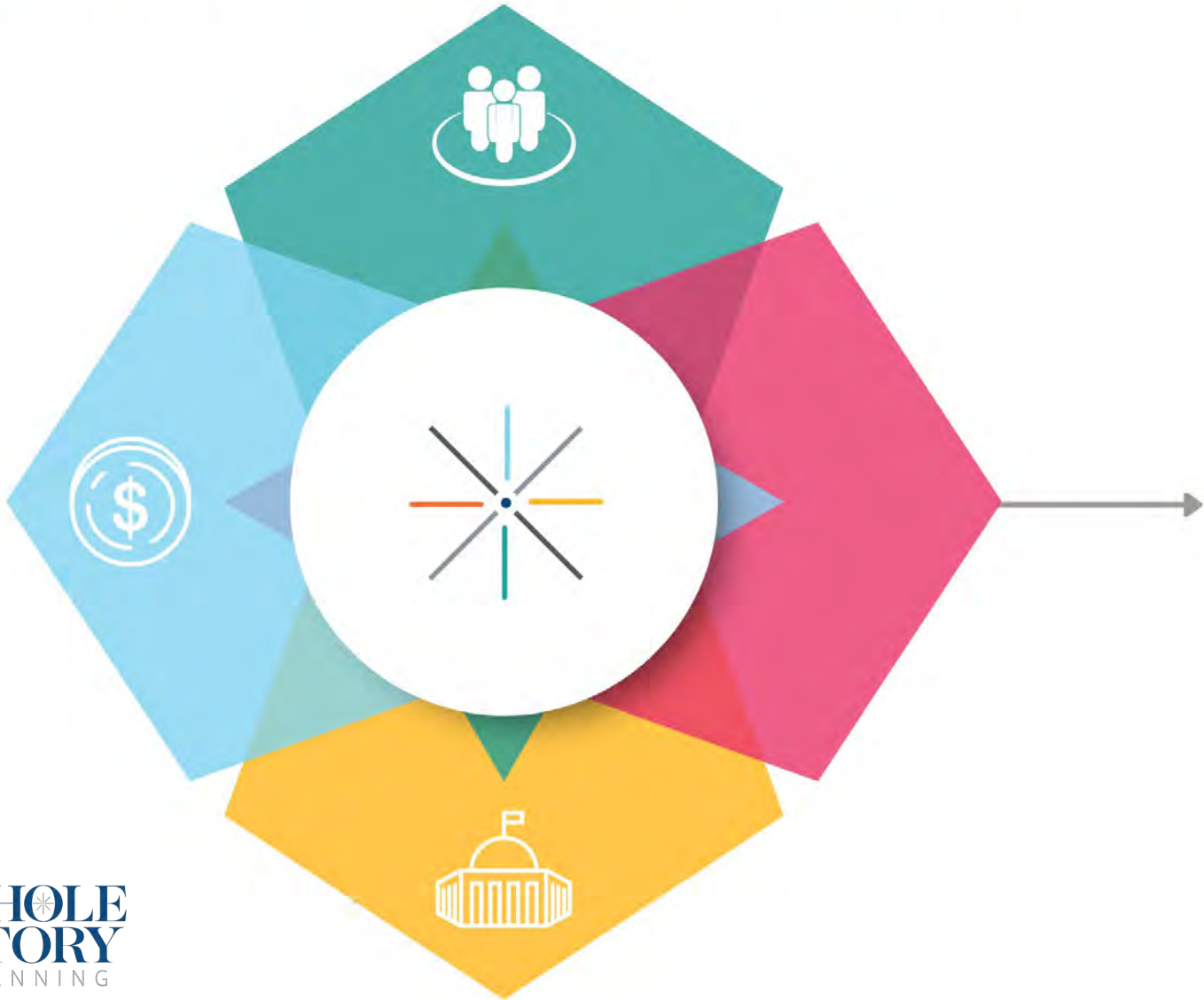
Social Security Disability  
Income (SSDI)


Medicaid

State

Local

# WHY WE'RE DIFFERENT:



 LEGAL COUNSEL

Will

Power of Attorney

Letter of Intent

Guardianship

Special Needs Trust

# WHY WE'RE DIFFERENT:



 OTHER RESOURCES

- Doctors
- Teachers
- Therapists
- Public Programs
- Private Programs



# WHY WE'RE DIFFERENT:



# DEVELOPING YOUR SPECIAL NEEDS

## Life Plan

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

## Life Plan

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

Child under age 18 with working parents

Parents' Income



Parents' Assets



Household Size



Child's Eligibility & Benefit Amount

Child age 18 or older with working parents

Adult Child with Special Needs Income

Adult Child with Special Needs Assets

Adult Child's Eligibility & Benefit Amount

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



In 2025, the benefit amount could be up to \$967 a month.

# RETIREMENT SOCIAL SECURITY

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

# DEVELOPING YOUR SPECIAL NEEDS

## Life Plan

A government benefits specialist can help estimate future costs.

Where You  
Live



The Care You  
Provide Now



Potential Annual  
Future Costs

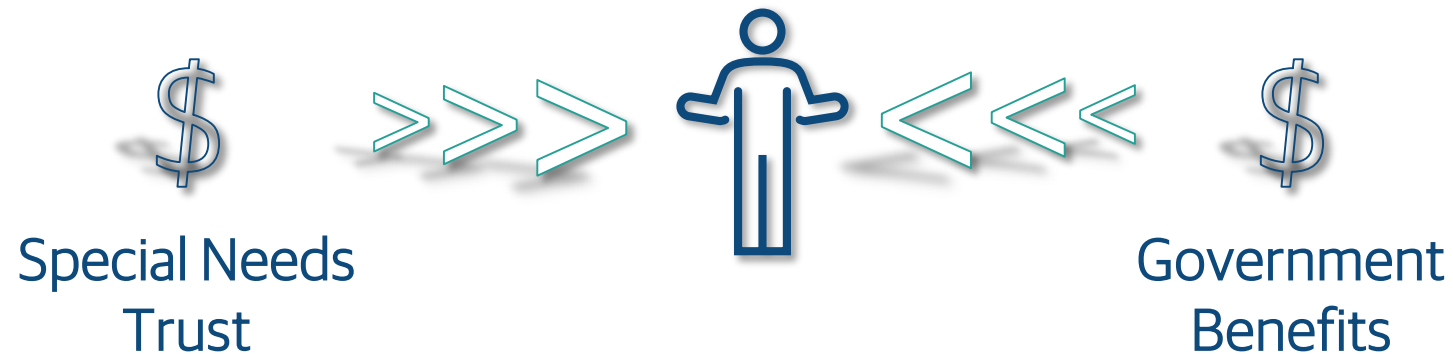
Government Benefits Specialist can help  
quantify costs and look for gaps



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

# THIRD-PARTY SPECIAL NEEDS TRUSTS

- 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 created so the remaining assets pass to family members if the primary beneficiary passes away.



# ABLE OR 529A PLANS

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

ABLE (ACHIEVING A BETTER LIFE EXPERIENCE) PLANS:

1. May be created any time if disability onset prior to age 26
2. Will not affect Medicaid eligibility no matter how large the account grows
3. If account balance is \$100,000 or more, it will affect Supplemental Security Income eligibility
4. Contributions are post-tax and are not tax deductible at the federal level (some states allow deductions). \$19,000 total contribution limit per calendar year.
5. Assets grow tax free and qualified distributions are tax free

# ABLE OR 529A PLANS

Used for:



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



**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?

# PLANNING FOR YOUR FINANCIAL 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 will work with you over time as your needs change.
4. Select a company that has a strong history and maintains the highest financial strength ratings in the industry.

# RECAP



## ASSEMBLE YOUR TEAM:

(1) financial professional (2) government benefit specialist (3) 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

Get More Info  
(and handouts)



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