



Helping American families achieve financial security while facing special needs and disabilities challenges

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Defining the special needs challenges

Across the United States, one in five children and adults — that’s 65 million people — will experience a special need or disability during their lifetimes.¹ Some may be living with a congenital issue such as autism or Down syndrome. Others may suffer from a brain trauma due to a motor vehicle accident or have lost limbs serving their country. For older adults, late onset diseases such as Parkinson’s, ALS, and Alzheimer’s may be the cause for special care. Aging in general — whether it’s related to a fall or dementia — often leads to these concerns.

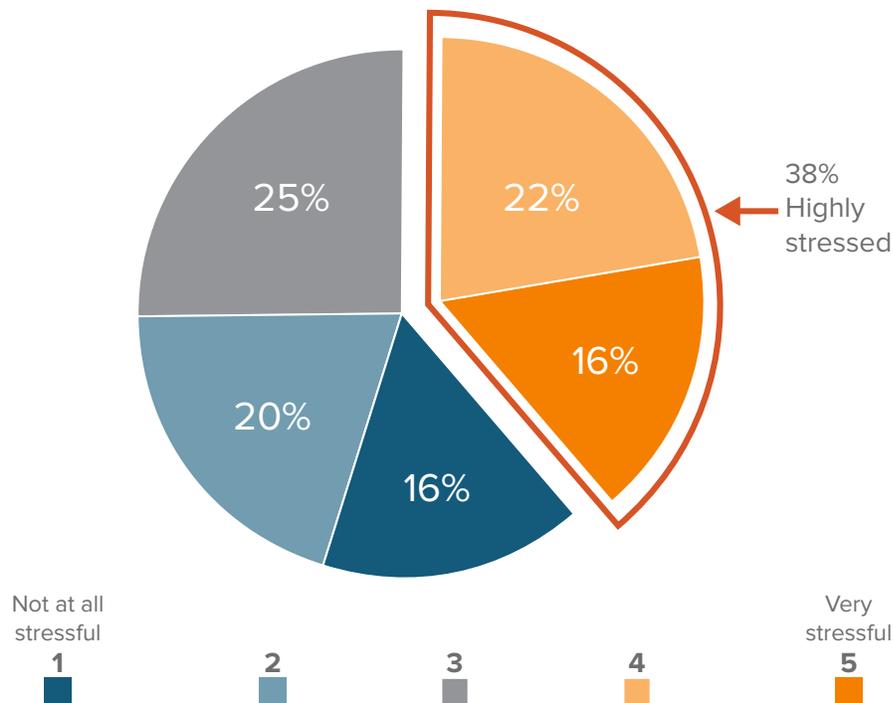
Without assistance from the government, non-profit organizations, or their employers, caregivers of these individuals face a tough, and often confusing, journey — especially when it comes to planning for their retirement and the care of their loved ones after they have passed away.

Complicating matters even more, certain conditions often manifest themselves with multiple special needs or disabilities.² For example, a child with autism may face vision or hearing-impairment challenges. A physically wounded veteran may battle cognitive problems or post-traumatic stress disorder. For a caregiver of someone with more than one special need or disability, the stresses and demands increase exponentially.

The good news is that medical and technological advances continue to enable better diagnosis and treatments. As a result, many may enjoy longer and fuller lives than in the recent past. According to the National Down Syndrome Society, medical advancements have dramatically increased the life expectancy of people with the condition during recent decades – from 25 in 1983 to 60 today.³ However, the costs to caregivers of that kind of success are many and high — emotionally, physically, and financially.

Emotional stress of caregiving

Base: Caregivers of Recipient
Age 18+ (n=1,248)



Source: *Caregiving in the U.S. 2015 Report* by AARP, the Public Policy Institute, and the National Alliance for Caregiving

1 U.S. Census Bureau data and respondents’ self-identification.

2 U.S. Census Bureau data and respondents’ self-identification.

3 National Down Syndrome Society website: <http://www.ndss.org/Down-Syndrome/Down-Syndrome-Facts>.

Average lifetime costs per person with:⁴

Autism:	\$1.4 million-\$2.4 million ⁵
Spina Bifida:	\$1.0 million ⁶
Severe mental impairment:	\$1.0 million
Cerebral palsy:	\$921,000
Vision impairment:	\$601,000

A growing concern and rising price tag

According to Autism Speaks, the cost of caring for a person with autism typically ranges from \$1.4 million to as much as \$2.4 million during that person's lifetime. By 2025, Autism's cost in the U.S., including treatment and lost productivity, will be \$461 billion annually — equivalent to 1 percent of the U.S. gross domestic product — according to a 2015 study by researchers at the University of California-Davis and the University of Denver. Very often, families carry most of the burden of paying for that care.



People who care for someone with special needs experience higher rates of health and emotional problems, and voluntary departures from the workforce. For many, caring for a person with special needs places them on the brink of a financial disaster when they should be preparing a plan to ensure a vision of how they will care for that person throughout the caregiver's lifetime and beyond.

4 Morbidity and Mortality Weekly Report: *Economic Costs Associated with Mental Retardation, Cerebral Palsy, Hearing Loss, and Vision Impairment – United States*, 2003.

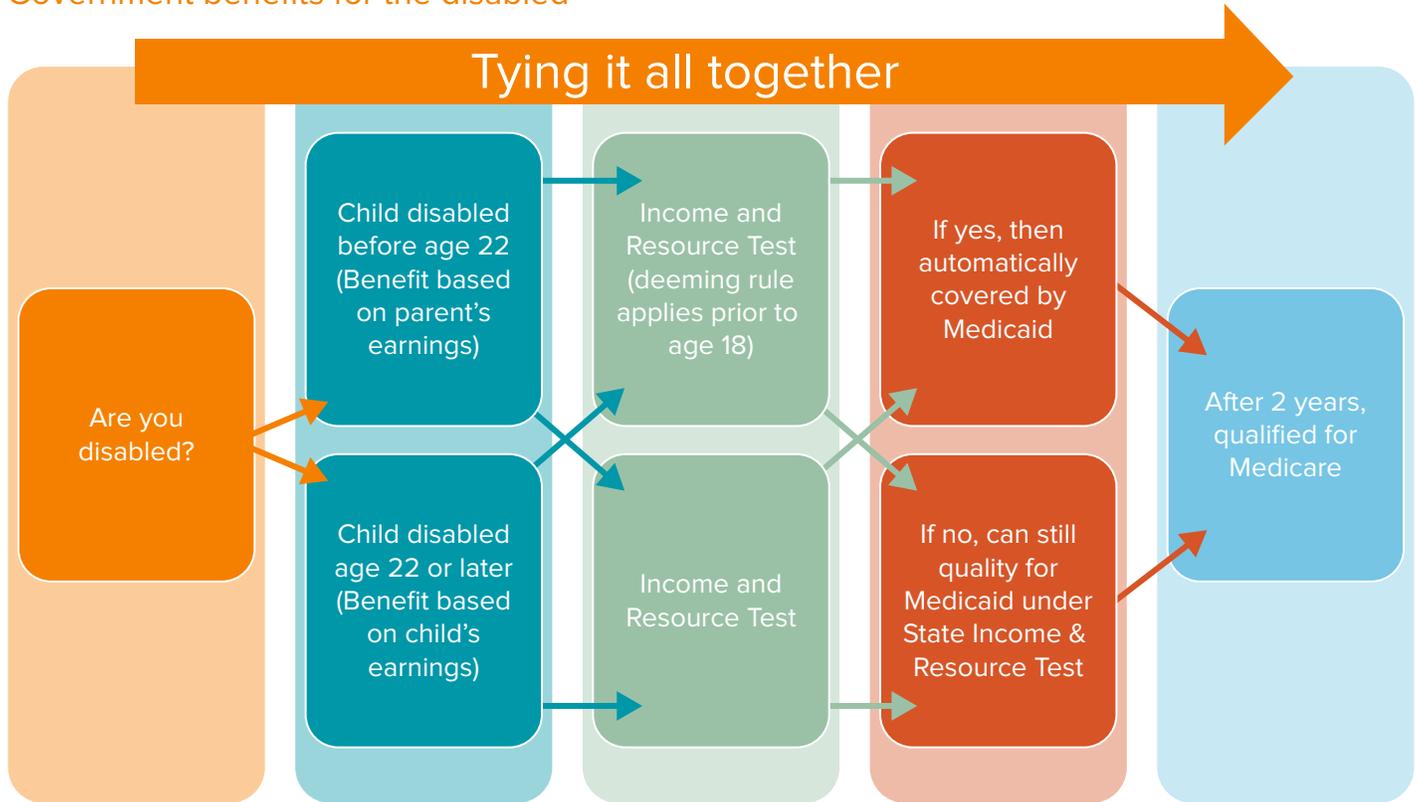
5 *Pediatrics*, March 2014, v. 133, issue 3.

6 Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities: *Living with Spina Bifida: A Glimpse for Prevention Campaign Partners*. 2006.

The complicated web of government assistance

While government assistance and entitlement programs can ease some of the money concerns of caregivers, the vast majority of expenses are borne by the family, and the rules underpinning federal support are often confusing and unrelated to costs.

Government benefits for the disabled



*Automatic Medicaid eligibility varies by state

For example, strict Social Security Administration guidelines on parents' income and assets could rule out Supplemental Security Income (SSI) for a person under the age of 18.

According to current Social Security guidelines, some of the income of the parents caring for a child with special needs or a disability could reduce the child's SSI payment or disqualify the child from receiving any payments. To qualify for SSI, an individual's resources cannot be more than \$2,000, and his/her monthly income generally cannot exceed the monthly SSI benefit (\$735 for a single individual during 2017).

Government benefits — key concepts

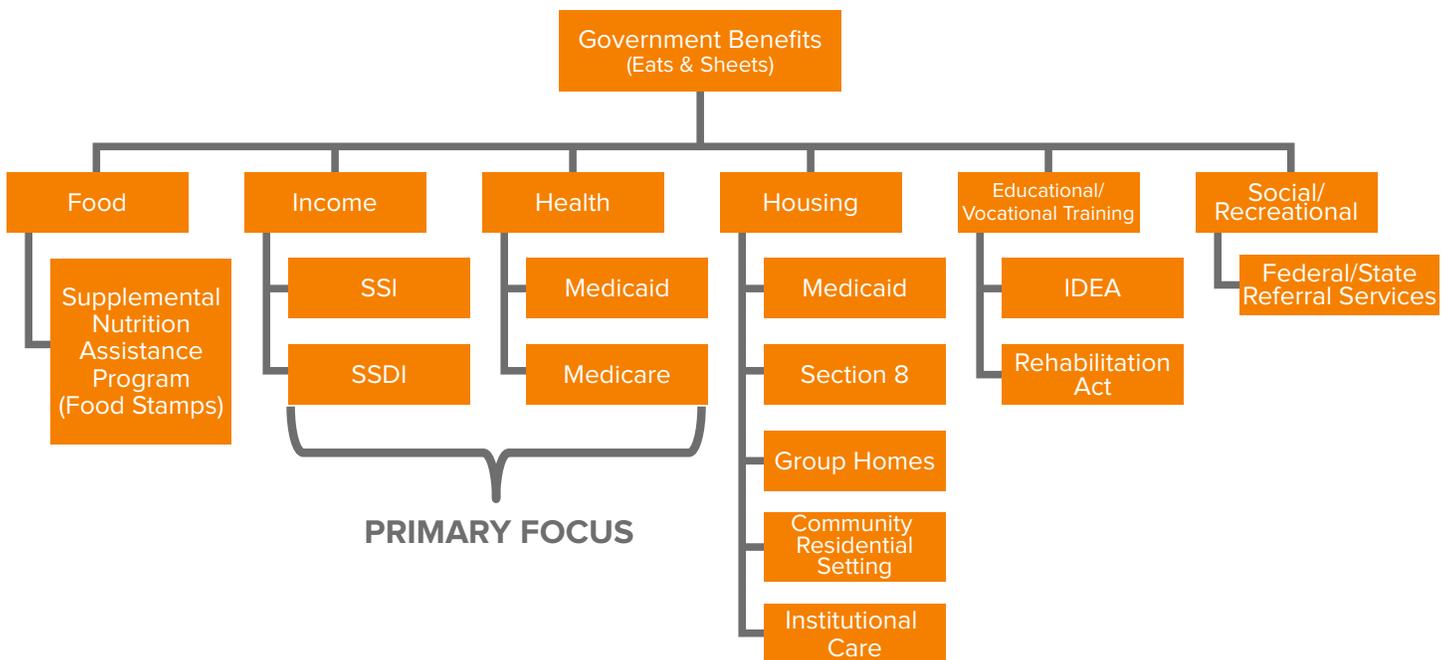
No.	Topic	Description
1.	Primary Programs	<ul style="list-style-type: none"> The primary government benefit programs include Social Security Disability Income (SSDI), Medicare, Supplement Security Income (SSI) and Medicaid.
2.	Disability Defined	<ul style="list-style-type: none"> Social Security defines disability as the inability to do substantial work because of a medical (physical or mental) condition or combination of impairments expected to last at least 12 months.
3.	Cash Benefit Program (SSDI-SSI)	<ul style="list-style-type: none"> SSDI and SSI represent cash benefits. To qualify for SSI, an individual's resources cannot be more than \$2,000 and an individual's monthly income generally cannot exceed the maximum monthly SSI benefit (\$735 for a single individual – 2017).
4.	Health Benefit Programs	<ul style="list-style-type: none"> Medicaid and Medicare pay for medical care for certain categories of individuals. Medicaid is means tested while Medicare is an entitlement program.
5.	Planning for Government Benefits	<ul style="list-style-type: none"> A child disabled prior to age 22 should apply for Social Security benefits upon reaching age 18. If the child's parents retire, become disabled or deceased, the child can qualify for SSDI based upon the parents' lifetime earnings. Upon age 18, the deeming rule no longer applies, and the child may qualify for SSI benefits and Medicaid if the child's income and resources meet the eligibility limits. After being disabled for 2 years, the child will also qualify for Medicare, which can supplement Medicaid benefits.



In some cases, the Social Security Administration or the state administers supplemental SSI payment programs. No supplemental payments are available, however, in Arizona, Mississippi, North Dakota, Northern Mariana Islands, and West Virginia.⁷

⁷ Social Security Administration, <https://www.ssa.gov/ssi/text-benefits-ussi.htm>

Government benefits (services)



Non-profit organizations dedicated to helping people with a specific special need, such as Autism Speaks, often offer free services to help caregivers find the best resources to deal with their medical care and treatment concerns. Unfortunately, they rarely are able to provide services that could relieve the short- and long-term economic burdens facing caregivers and people with special needs.

The concerns and costs of providing care to children and young adults with special needs

Fifty percent of parents of children with special needs report that the cost of care presents significant economic challenges that impede their ability to save for retirement, education for other children, or financial emergencies as well as any long-term financial care and security for the person for whom they are caring.⁸

The impact has a ripple effect. Without financial and educational assistance from the government, non-profit organizations, or their employers, caregivers are more likely to miss work due to illnesses brought on by the additional stress and fatigue caused by the financial difficulties of tending to people with special needs.⁹ Further, caregiving issues result in annual losses of at least \$25.2 billion in productivity for American businesses because of absenteeism, workday disruptions, employees leaving the workforce, and other factors.¹⁰

Another exacerbating factor is that people with special needs who reach 22 years old may “age out” of services and benefits, especially those related to the Individuals with Disabilities Education Act, which provides children with disabilities the opportunity to receive a free, appropriate public education, just like other children. When this happens, families face a slew of harsh economic realities about the immediate needs that their adult children have as far as healthcare, housing, transportation, social interactions, and financial security that will promote their independence.

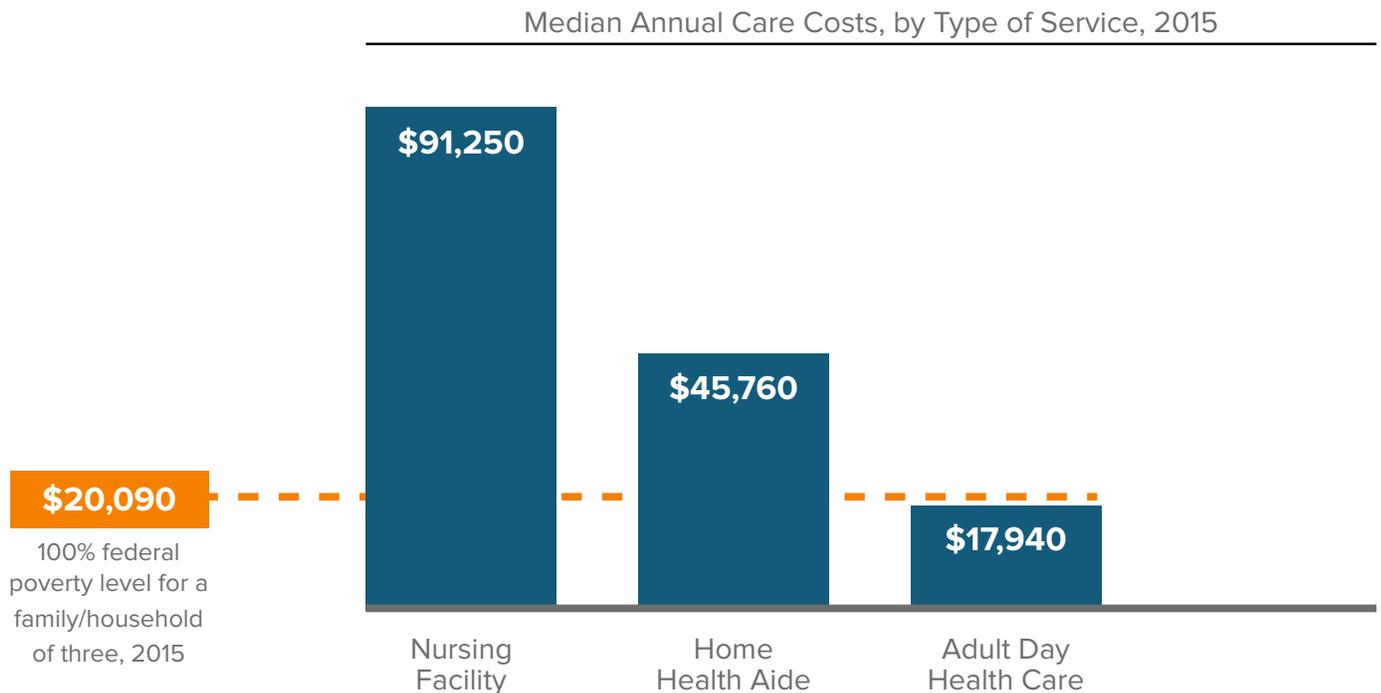
⁸ National Alliance for Caregiving in collaboration with AARP: Caregiving in the U.S. 2009 – A Focused Look at Those Caring for a Child with Special Needs under the Age of 18.

⁹ AARP 2015 Report Caregiving in the U.S.

¹⁰ Gallup-Healthways Well-Being Survey: Caregiving Costs U.S. Economy \$25.2 Billion in Lost Productivity.

Filling in the financial gaps

Long-term services and support are expensive, often exceeding what beneficiaries and their families can afford



SOURCES: Genworth, *Genworth 2015 Cost of Care Survey* (Richmond, VA: Genworth Financial, Inc., April 2015), https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/130568_040115_gnw.pdf; U.S. Department of Health and Human Services, 2015 Poverty Guidelines, <https://aspe.hhs.gov/2015-poverty-guidelines>.



While daunting, there are ways to fill the gaps to ensure the financial security of a person with special needs without negatively affecting government benefits. For instance, there are a growing number of financial planners who specialize in special-needs planning, including those with the **Chartered Special Needs Consultant**, or “ChSNC,” designation.

In addition, **accident insurance** provides coverage for out-of-pocket expenses after they experience a debilitating accident.

A **Special Needs Trust** enables the trust to be set up for the benefit of the individual with special needs. Funds can be used from the trust and not jeopardize government benefits. The trust can hold various types of assets, including cash, investment portfolios, and life insurance proceeds.

Additionally, Congress in 2014 created a new savings opportunity for people with disabilities through the passage of the **Achieving a Better Life Experience (ABLE) Act**. ABLE allows the person with disabilities or a legal representative to establish tax-advantaged savings accounts of up to \$100,000 without affecting SSI. If SSI is not an issue, limits are generally expanded to between \$250,000 and \$350,000.

“The ABLE Act created greatly improved financial opportunities for individuals with disabilities. For the first time, individuals with disabilities and their families can save money for the future without jeopardizing eligibility for critical government supports.”

— Sara Weir, president of the National Down Syndrome Society.

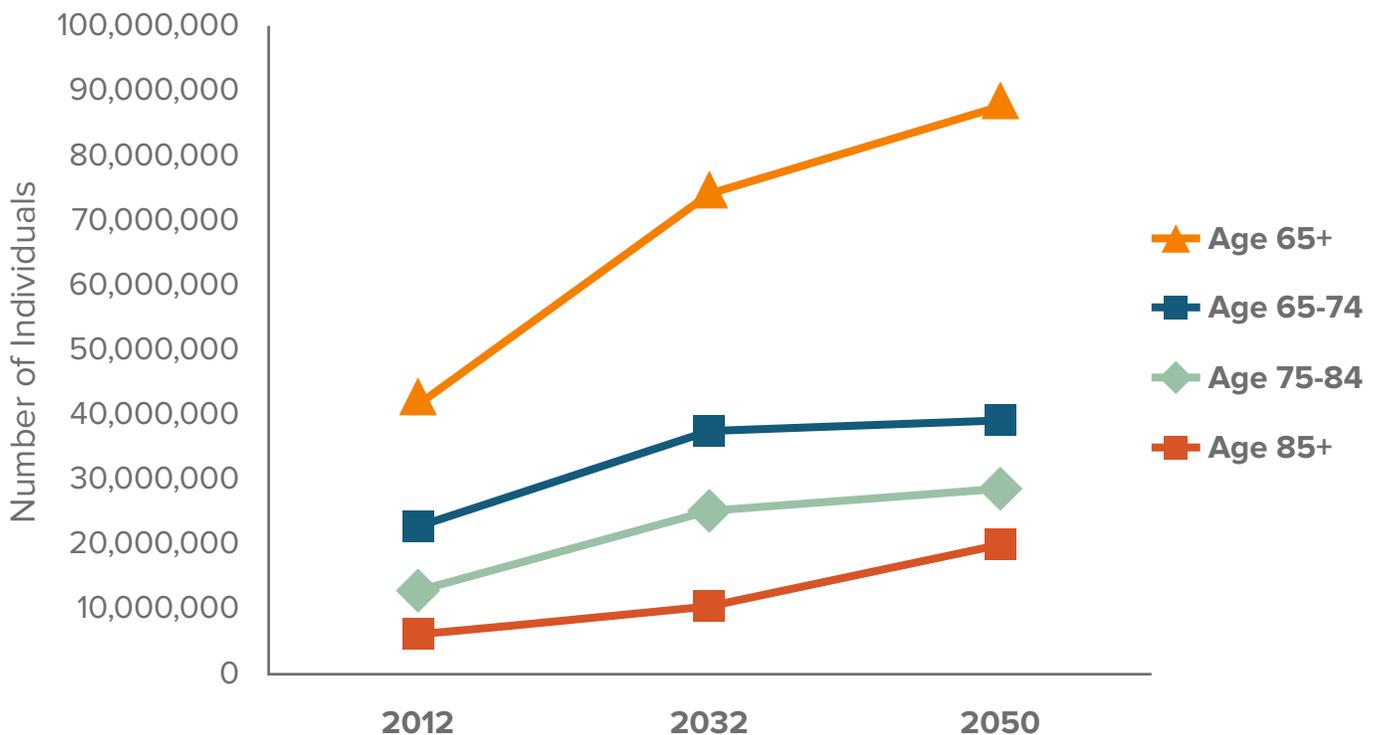
In addition, depending on where a family lives, additional state or municipal benefits and programs may be available.

Ensuring the proper structuring of any vision of ongoing care, including how assets are titled or how a beneficiary may receive such assets, requires careful consideration of associated legal matters to eliminate any possibility of compromised integrity. In many cases, non-profit organizations and specialized financial services advisers can help caregivers navigate through these issues, as can employers whose workforce include employees who care for people with disabilities.

Caregiving for the aged

Every day, another 10,000 “Baby Boomers,” people born from 1946 to 1965, reach the age of 65.¹¹ That trend will continue until almost 2030.

The 65 and over population will more than double and the 85 and over population will more than triple by 2050



SOURCE: A. Houser, W. Fox-Grage, and K. Ujvari, *Across the States 2013: Profiles of Long-Term Services and Supports* (Washington, DC; AARP Public Policy Institute, September 2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf



¹¹ Pew Research Center: www.pewresearch.org/daily-number/baby-boomers

For the most part, Boomers are healthier than previous generations of people in the same age group. On average, they tend to live longer than their parents and grandparents. As a result, many Boomers will experience conditions such as dementia, strokes, and other age-related special needs that will require ongoing attention and treatment.

If those situations occur, the special needs caregiving situation is the reverse of the typical scenario of a younger parent looking after a child. Instead, more and more middle-aged adults, and even post-retirement Boomers, now provide care for their elderly parents with disabilities. In many cases, those parents have limited financial means.

For Generation X or the “Sandwich Generation” — the group of adults in their 40s and 50s with non-adult children and aging parents — who are caring for their parents, only 28 percent say they can live comfortably on their income while providing care. Conversely, 41 percent of Gen Xers not caring for older adults report they live comfortably.¹²

As is the case with younger people with special needs, caregivers of elderly relatives confront many of the same concerns regarding support for financial, work, and other related issues — and look for the same solutions.

The effect on business

Providing care for people with special needs is a daunting — and often lifelong — challenge. Many of the stresses associated with caregiving can be mitigated through early planning and continuing awareness and education. Financial experts strongly advise that caregivers of people with special needs to start preparing as soon as possible. In cases where a doctor may diagnosis a pre-birth congenital issue, advisers encourage financial planning before the baby is born.

Due to the complexity of these challenges, and the likelihood that they will have a negative emotional and financial effect on caregivers, people increasingly are seeking employer-based solutions and the services of specialized financial planners who will provide them with peace of mind, both now and in the future.¹³

Studies show that caregivers suffer an 18.5-percent decrease in productivity and are more likely to quit their jobs to tend to their responsibilities.¹⁴

64 percent of working parents who care for a special needs child believe that those responsibilities negatively affect their work performance.¹⁵



12 Pew Research Center: The Sandwich Generation, 2013. www.pewsocialtrends.org/2013/01/30/the-sandwich-generation

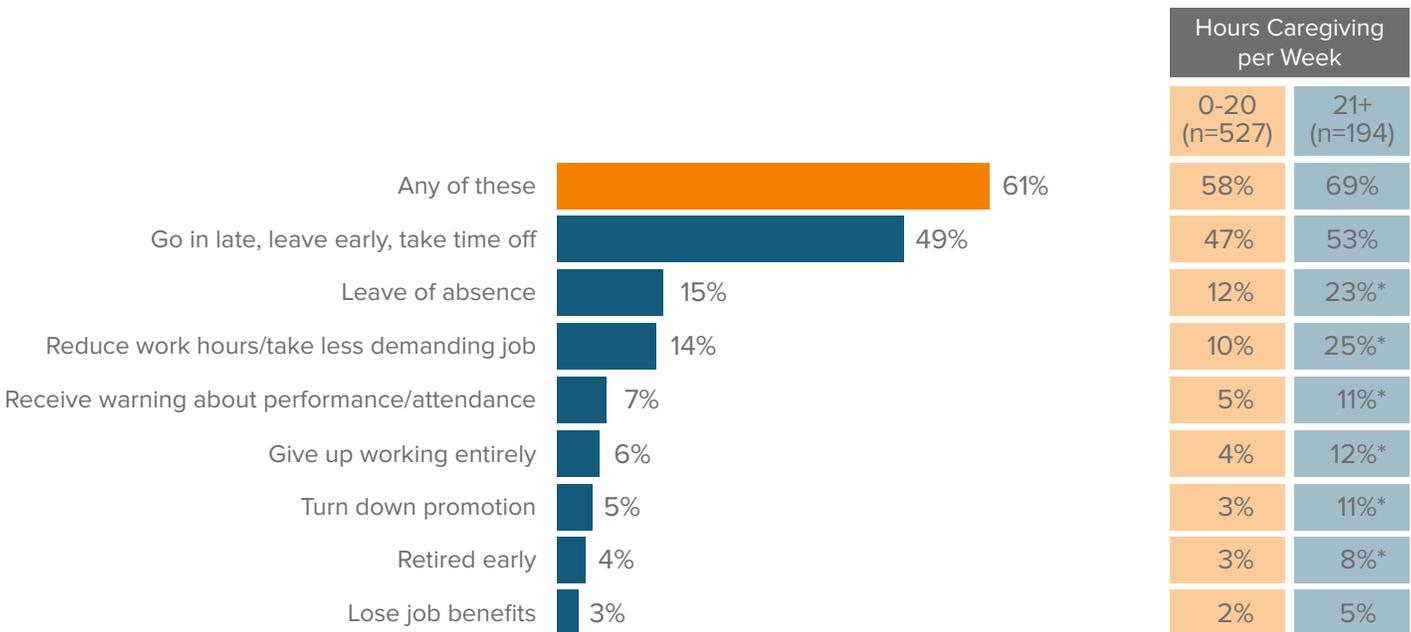
13 AARP 2015 Report Caregiving in the U.S.

14 Coughlin, J. (2010). *Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management*.

15 Care.com and National Family Caregivers Association: *State of Care Index*. 2009.

Work impacts due to caregiving

Base: Working Caregivers of Recipient Age 18+ (n=724)



Source: *Caregiving in the U.S. 2015 Report* by AARP, the Public Policy Institute, and the National Alliance for Caregiving

Yet few companies in the U.S. are holistically inclusive or aware of the issues facing employees who are caregivers of people with special needs. Companies that fail to reach out to these employees are missing an opportunity to positively affect productivity and strengthen culture, employee relations, corporate responsibility, recruiting, marketing, and customer relations.

Extending a helping hand to caregivers is ultimately a sound, long-term business decision for companies and other organizations that want to ensure they attract and retain talent.

Voya Financial steps up

Voya Financial understands the challenges confronting its employees and others who care for people with special needs and stands ready and prepared to help them plan for their financial and quality of life as well as the people they care for.

“We are ensuring that we are accommodating internally with our benefits and talent-acquisition efforts,” says Heather Lavalley, president, Voya Tax-Exempt Markets, who also leads the company’s People With Special Needs task force. “Being inclusive is part of who we are as a company, and we want employees to be proud of these efforts as we move forward.”

While employer-based solutions are critical to easing the burdens of caregivers in the workforce, those programs and services need to be coordinated with government benefits and non-profit offerings. More important, any approach to helping caregivers should be a holistic one that addresses issues both in the workplace and at home.

Employers should assume the role of a navigator to help their employees successfully and efficiently steer through their caregiver concerns. Similar to Voya's efforts, in this role, companies can:

- Provide one-stop educational access to resources and information on caregiving.
- Reduce the emotional stress of caregivers by helping employees understand complex legal and financial issues relating to caregivers and people with special needs.
- Open or create portals that provide access to support and education networks.
- Advocate for the concerns of working caregivers and people with special needs.
- Increase awareness of service providers who are experts in dealing with people with special needs.
- Provide increased employment for people with special needs and disabilities.
- Offer access to financial solutions involving quality of life and care issues.
- Providing flexible work schedules for caregiver duties.
- Eliminate perceived or real biases of performance and productivity toward employees caring for people with special needs.
- Create understanding among employees of the challenges facing co-workers who care for people with special needs.
- Foster an atmosphere of encouragement that allows employees caring for people with special needs to be open about their responsibilities.

Nine out of 10 parents of children with special needs say they receive little or no financial support beyond their incomes. Many in that group also say that caring for a person with special needs gravely impairs their ability to plan and save for retirement.

Improving the financial wellness and retirement goals of caregivers is a national challenge that requires coordinated support and efforts from individuals, employers, government, and the financial services industry. All solutions must offer comprehensive short- and long-term financial planning options to employees who are caregivers, so that they can ensure the quality of life goals for people with special needs in their lives as well as their own — during their working years, retirement, and beyond.

The matter of people of special needs is a critical factor in the ability of millions of Americans to plan and fund their retirement. It can no longer be swept under the carpet. Neither can the concerns and often overwhelming responsibilities Americans face every day in caring for people with special needs. Together, as employers, co-workers, relatives, and friends, U.S. companies, non-profit organizations and legislators can deliver the services, resources, and legal support to give caregivers the help they deserve to ease the demands of caring for a person with special needs.

At Voya Financial, there is an ongoing effort to examine and modify policies and benefits that support caregivers and employees with special needs. Voya Financial also continues to provide access to information, training, and other resources to help employees and their families prepare for their unique retirement situations as well as find educational resources. In addition, during 2017, Voya plans to offer its informational and caregiver retirement-planning services publicly via a series of pilot programs.

Across America, companies, legislators, non-profits and other groups are well positioned to do their part in order to help ease the emotional and financial burdens faced by people with disabilities and by caregivers of people with special needs.

“Ensuring that we are properly serving those with special needs — along with their families, friends, and other caregivers — is not only the right thing to do, it also positions Voya as America’s Retirement Company serving all Americans.”

— Rodney O. Martin, Jr., chairman and chief executive officer, Voya Financial

Profiles in caregiving

- Approximately 43.5 million caregivers have provided unpaid care to an adult or child in the last 12 months.
- 16.8 million people are caring for special needs children under 18 years old.¹⁶
- 72 percent of caregivers of children with special needs are female with an average age of 40.6 years.¹⁷
- 51 percent of caregivers are responsible for one child under 18; 36 percent care for two people (including adults), and 12 percent care for three or more.¹⁸
- On average, caregivers spend 29.7 hours a week helping children with special needs younger than 18 years.¹⁹
- Female caregivers are 2.5 times more likely than non-caregivers to live in poverty and 5 times more likely to receive Supplemental Security Income.²⁰
- 47 percent of working caregivers indicate an increase in caregiving expenses led to their depleting some or all of their savings.²¹
- 75 percent of caregivers report changes in their employment status, including reducing hours worked, accepting a less demanding position, or quitting.²²

16 National Alliance for Caregiving in collaboration with AARP: *Caregiving in the U.S. 2009 – A Focused Look at Those Caring for a Child with Special Needs under the Age of 18.*

17 National Alliance for Caregiving in collaboration with AARP: *Caregiving in the U.S. 2009 – A Focused Look at Those Caring for a Child with Special Needs under the Age of 18.*

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19 National Alliance for Caregiving in collaboration with AARP: *Caregiving in the U.S. 2009 – A Focused Look at Those Caring for a Child with Special Needs under the Age of 18.*

20 Study conducted by researchers at Rice University and data compiled from the Health and Retirement Study funded by the National Institute of Aging.

21 National Alliance for Caregiving and Evercare: *Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving.* March 2009.

22 National Alliance for Caregiving in collaboration with AARP: *Caregiving in the U.S. 2009 – A Focused Look at Those Caring for a Child with Special Needs under the Age of 18.*



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