

An **Overview** of Key Findings

Caring for a Sibling with a Disability

Easter Seals Siblings Study

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Introduction

More than 65 million people – 29 percent of the U.S. population – provide care for a chronically ill, disabled or aged family member or friend during any given year, and spend an average of 20 hours per week providing care for their loved one.¹ Many are the primary care providers for an adult brother or sister. Yet far more attention is typically paid to caregivers in the role of spouse, parent or adult child. While the caregiver role can be fulfilling, even inspiring, it can also be a great deal of work.

In order to better understand the unique issues faced by adults with disabilities and by their siblings, the Easter Seals Sibling Disability Study survey, sponsored by Massachusetts Mutual Life Insurance Company (MassMutual), was conducted by Ipsos Public Affairs, one of the leading consumer research companies in the U.S. The survey reveals that many adults who have a sibling with special needs already are, or at some point will be, their siblings' primary caregivers. Many feel financially unprepared to take on this role, and wish they knew more about how to plan for their sibling's care and finances.

This key findings overview highlights some primary issues that siblings are facing and focuses on the many challenges related to life care planning.

¹ Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP; November 2009

A special bond

The bond between siblings is long-lasting and powerful.

Brothers and sisters are a child's first peer group, his teachers, confidants, and rivals. Siblings share family ties and, most often, the same home environment. Their shared experience over a lifetime can provide irreplaceable continuity and support.

Siblings, however, though they may be very close, are never exactly alike. Birth order, age difference, gender, personality and other factors influence the dynamic of the relationship. These factors help to shape the person the child will become. Because siblings have so much in common, their differences stand out all the more. If a child feels her sibling is prettier or smarter, more talented or loved, she may be jealous. Yet if a child has too many advantages, she may experience guilt.

Siblings continually redefine their relationship as they go through life's stages. When young, they may be close companions. As adolescents trying to find their identities, they may challenge one another. While busy establishing their own households, they may be more distant. In old age, they may once again become very close as shared reminiscences gain importance.

When one sibling has a disability, however, the usual dynamic may change. Who will be the caregiver if the person with the disability is not fully independent as an adult? Nearly half of the time, caregiving responsibilities are taken on by parents, but what happens when the parents are no longer there? In one of four cases, a sibling will step in. Moreover, nearly one in three siblings expects to become the primary caregiver at some point in the future.

"My immediate family would not get together as much, or make the effort to get along better if it were not for the presence of my younger disabled sister (DS). Personally, I just love my DS. She has a fantastic sense of humor, and is a joy to be around."

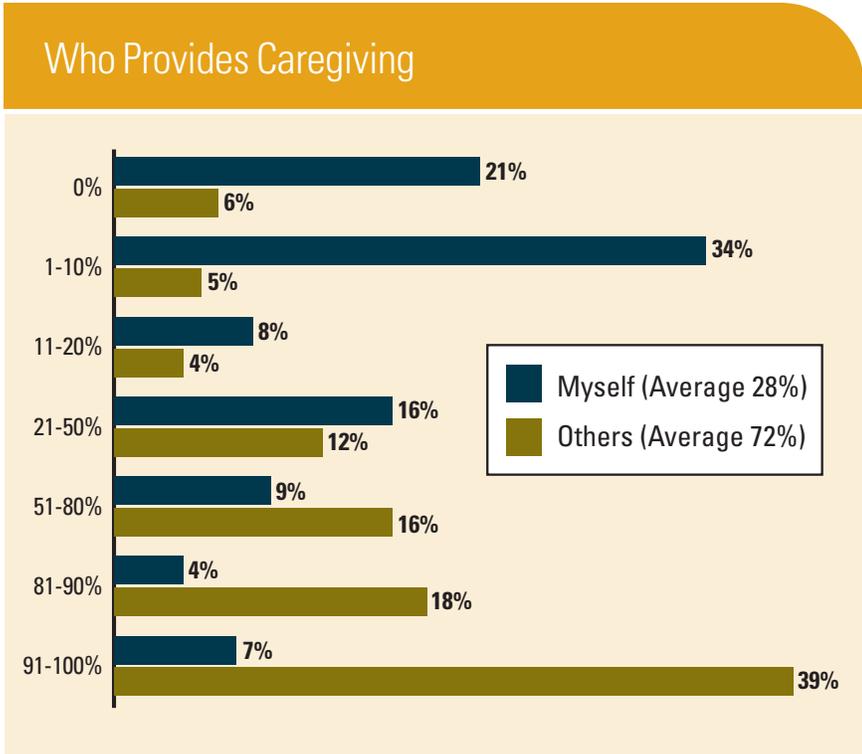


Caregiving: A big responsibility

Caregiving is a major challenge for adults with a developmentally disabled sibling. Only about one in ten say their sibling lives independently, with or without a partner, spouse, or paid attendant. Nearly six in ten report that their siblings live with family members, usually with parents or a guardian. As parents age, responsibility for caregiving is more likely to fall on a brother or sister. And caring for a sibling with a developmental disability takes time and effort. Nearly two-thirds report that their siblings need some or a lot of daily help with activities of daily living. Nearly half of those whose siblings have a developmental disability say that they need paid professionals to provide daily care or vocational support, and a third say they need professional behavioral support.

When it comes to financial matters, those with a sibling with a developmental disability are much less likely than those in the general population to say that their sibling is able to work for pay, to manage their finances, and to be financially independent and secure. Less than three in ten say that their sibling is currently working, including just eight percent who are employed full-time.

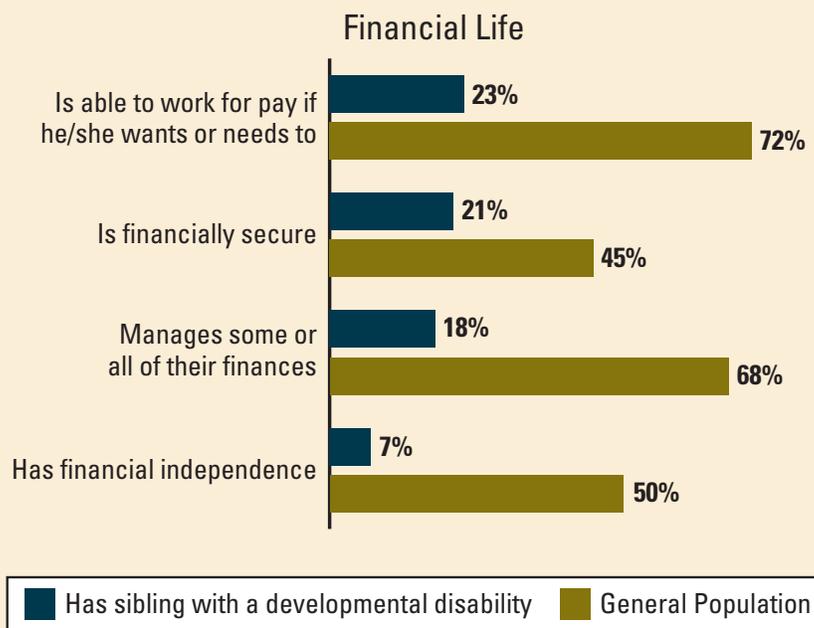
A majority of siblings (55%) say that they provide 10% or less of the caregiving for their sibling with a developmental disability, including 21% who say that they do not take on any of the caregiving responsibilities. However, only one in five (20%) respondents with a disabled sibling say that they provide the majority of the care for their sibling, while nearly three quarters (73%) say that others provide the bulk of the caregiving.



“He has been a constant source of inspiration.”

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Lifestyle and Ability Level of Sibling: Financial Life

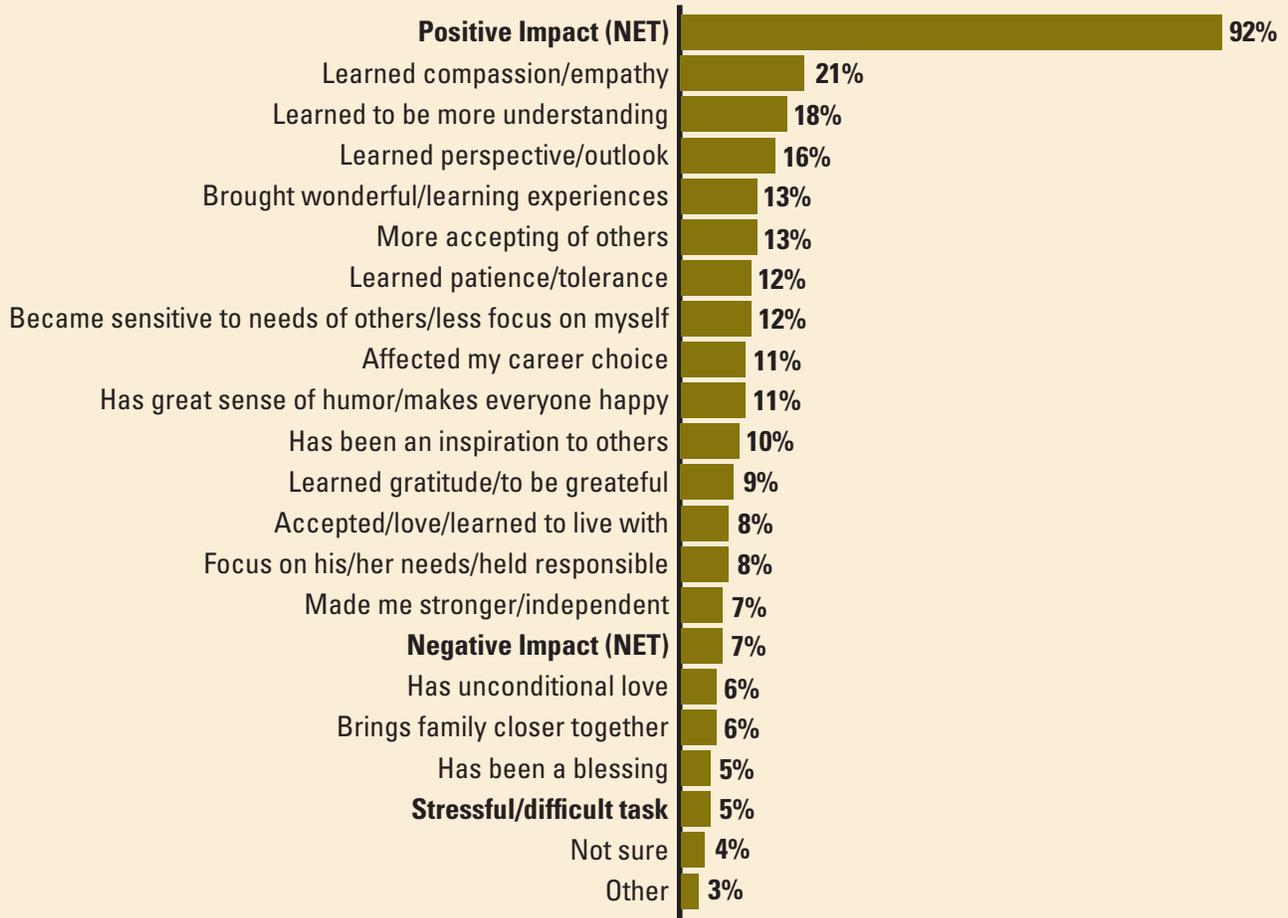


“He has made me who I am: patient, caring, adaptive, focused, and inclusive. And I’m grateful for how life has shaped me because of who he is. His being a part of our family will hopefully make my children all those wonderful things too.”

There are also notable gaps between these two audiences when it comes to home and family life, particularly with regard to having the ability to make their own life decisions, owning or renting their own residence, and having a spouse or partner. For example, whereas over half of the general population reports that their siblings have spouses or life partners, only seven percent of those with a developmentally disabled sibling say the same. While over three-quarters of the general population think that their siblings can make their own life decisions, less than one in five of those with a developmentally disabled sibling agree.

Transportation assistance, ongoing medical care, and assistance managing finances are the top three service areas currently needed, and services that will continue to be needed in the future. While just under half report that their sibling currently needs paid caregivers providing daily care as well as assistance in gaining or maintaining employment, these are needs that respondents anticipate their disabled siblings needing more of in the future. Only one in ten says that their sibling doesn’t currently need any of these services, nor will they need them in the future.

Why Quality of Life Has Been Impacted: Overall Positive Impact



Having a sibling with a developmental disability presents far-reaching challenges. About one in five say it has had a negative impact on the cohesiveness of their family, their relationship with their parents, their interactions with extended family or the quality of their lives. Many cite increased stress and having a limited social life as some of the additional challenges they face in caring for their sibling with a disability.

Despite these challenges, roughly eight out of ten say they have a close relationship with their sibling with a disability and that this relationship enhances their life, compared to only six out of ten of the general public respondents. Six in ten say having a sibling with a disability has a positive impact on their quality of life, helping them develop patience, understanding, compassion, and providing perspective.

Among respondents who say that their disabled sibling has positively impacted the quality of their lives, the top reasons for this positive impact include learning to be more understanding/compassionate/patient, learning a new perspective or outlook, being more accepting of others, and wonderful/learning experiences.

Financial concerns

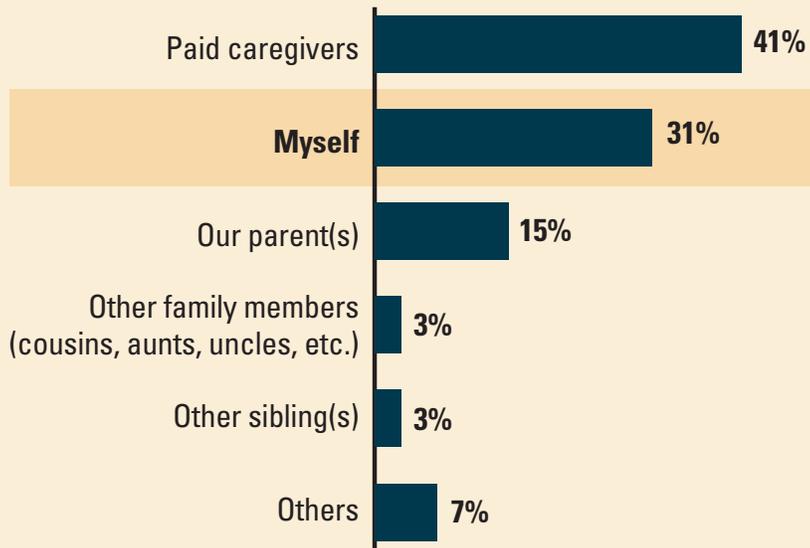
A majority of respondents among both populations are also worried about being able to meet their long-term financial goals.

In these difficult economic times, financial concerns are an ever-present worry for most Americans. Struggling to get by in the present moment, they are likely to be putting off long-term planning. Dealing with the day-to-day challenges of disability tends to intensify the problem. Majorities of respondents both with and without a sibling who is developmentally disabled agree that they should be doing more to save money for the future, but that right now they are just struggling to get by. Among those with a developmentally-disabled sibling, those with lower incomes, those without a college education, and those aged 35-54 tend to be more likely to agree.

A majority of respondents among both populations are also worried about being able to meet their long-term financial goals. Those most likely to agree include those with lower household incomes. About four in ten are confident that they are doing a good job of preparing for retirement. An even larger majority of respondents among both populations want to be actively involved in all of their financial decisions, especially if they have a sibling with a disability. In particular, over 90 percent of Sibling Survey respondents with a college degree and those serving as trustee feel this way.

While most people agree that they always think about what would be best for their immediate family when making financial decisions, this is especially true for those who are their sibling's primary caregiver, and those who live with their sibling. Among those with a sibling who is disabled, a majority agree that they wish they knew more about how to plan for their sibling's care and finances and worry about the cost of caring for their sibling. Those most likely to be eager for more information about such planning are those who expect to take on the role of primary caregiver or trustee in the future. They are also more likely to be worried about the cost of caring for their sibling. Among this same group, four in ten agree that taking care of their special needs sibling has caused their family great financial stress.

Sibling's Future Primary Caregiver

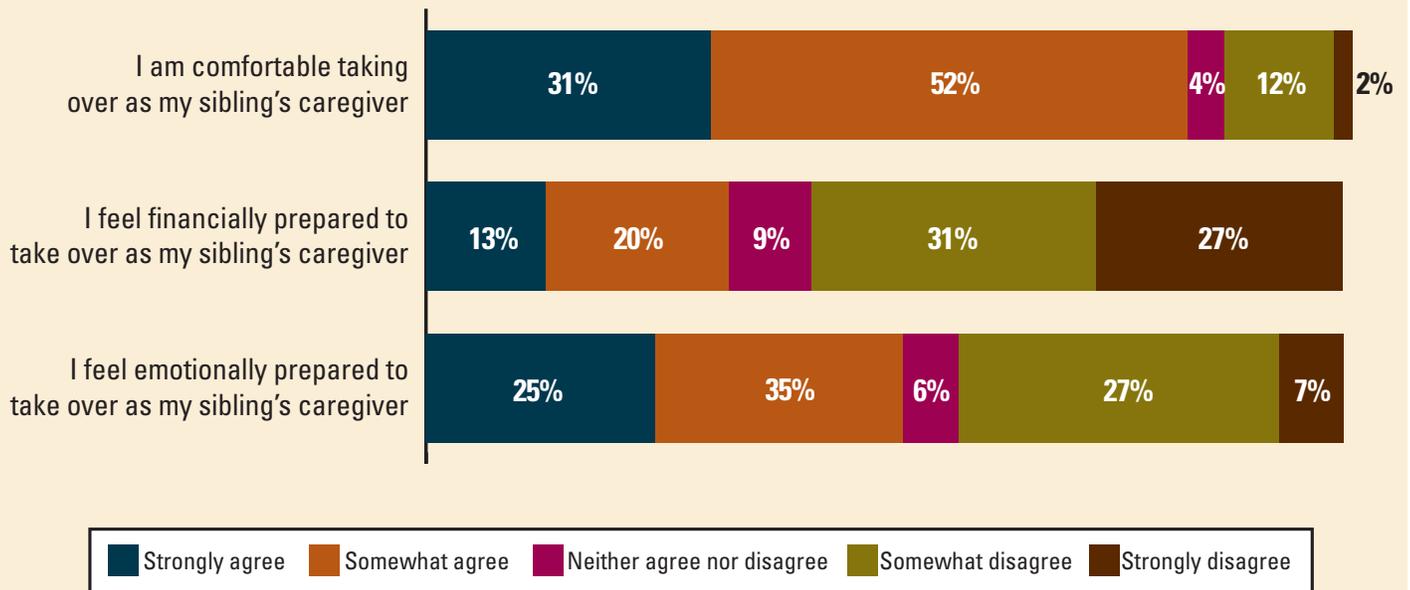


Among respondents who have a sibling with a developmental disability, 41% anticipate paid caregivers helping out with their siblings in the future, followed by 31% who expect to care for their sibling(s) themselves. More than half (52%) expect a family member to care for their disabled sibling in the future.

Among respondents who have a sibling with a developmental disability, more than half expect a family member to care for their disabled sibling in the future. Four in ten expect a paid caregiver to fulfill this role.

Having enough money is by far the most worrisome aspect of caring for a sibling with a disability. While over eight in ten respondents report being comfortable taking over as their sibling's future caregiver, only about a third actually feel financially ready and 60% feel emotionally ready.

Feeling Prepared to Take on Caregiving Role

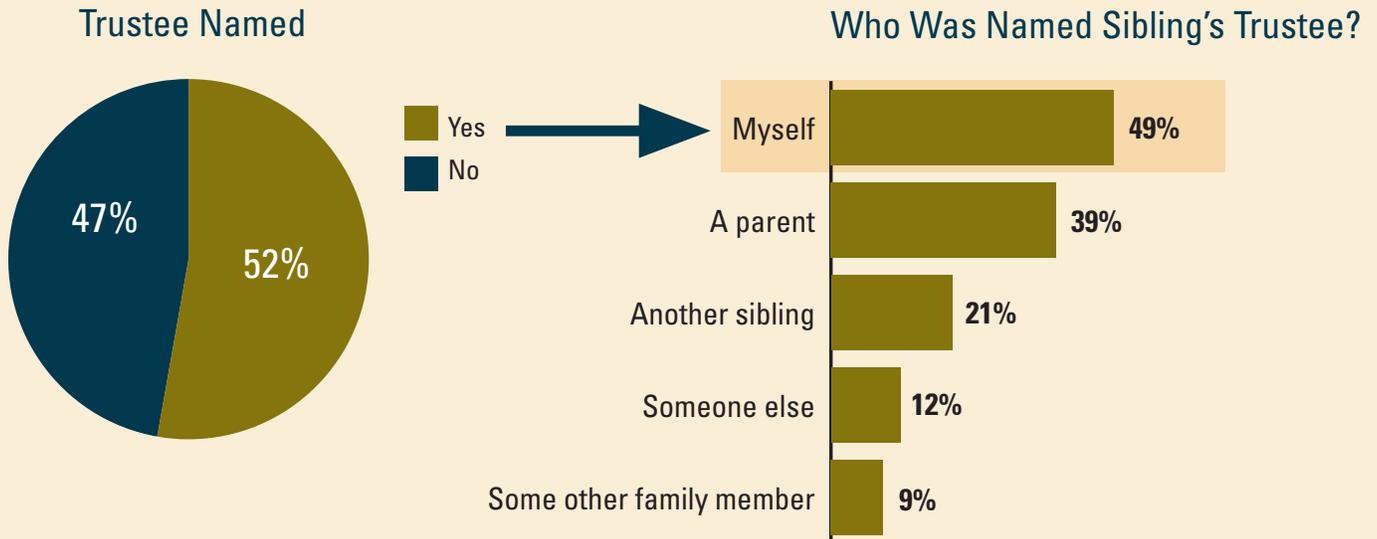


83% of respondents report being comfortable taking over as their sibling's future caregiver, while only 33% and 60% feel financially and emotionally ready, respectively.

A majority of respondents who have a sibling with a developmental disability have named a trustee to oversee their siblings' finances. In most cases, the trustee is a family member. Those who are the primary caregiver for their sibling are most likely to be that family member.

"Now that I have my own children I am on the brink of inheriting my sister's care. I will take good care of her willingly, but the decision making related to her living situation feels stressful. I am frustrated that my parents have not provided a living situation for her in which she thrives."

Financial Trustee Named



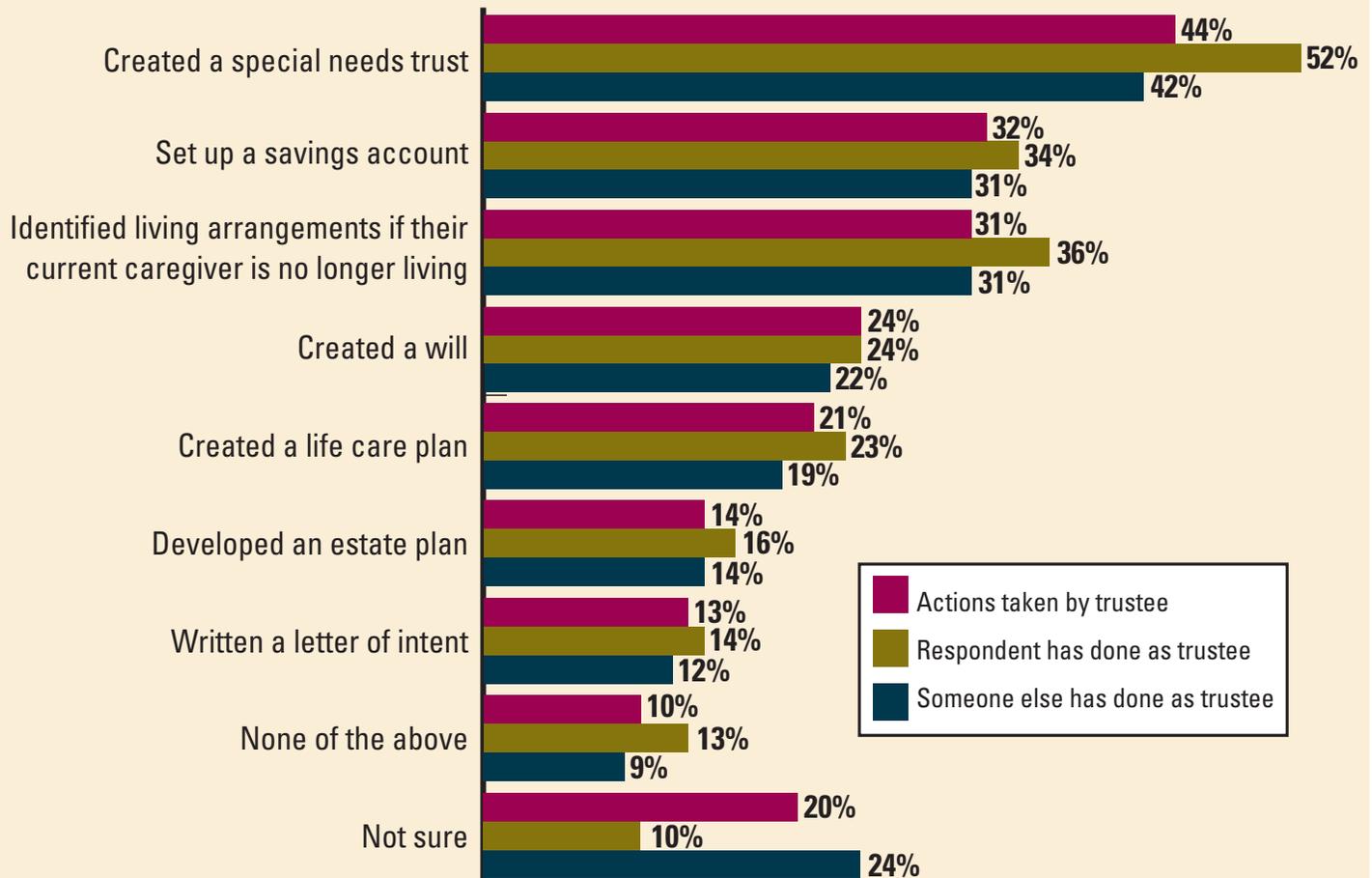
A majority of respondents who have a sibling with a developmental disability have named a trustee to oversee their siblings' finances. Among them, nearly half say that they are their sibling's trustee, while 39% say that a parent and 21% say another sibling was named to take on this role. Those most likely to say that they were named as their sibling's trustee include those who are the primary caregiver (80%), married adults (58%), and those with a household income of at least \$50,000 (56%).

"There have been experiences and doors opened because of my brothers' autism. However, due to my mother not providing adequate care or financial support, I feel held back from making life decisions because of the potential care my brothers may need."

Those most likely to say that a trustee has been named for their sibling include:

- Those with a sibling with an intellectual disability (65%) or multiple disabilities (65%)
- Those with a sibling who needs a lot of support for daily activities (60%)
- Those who use paid professionals as the primary caregiver for their disabled sibling (80%)

Trustee Activities Completed

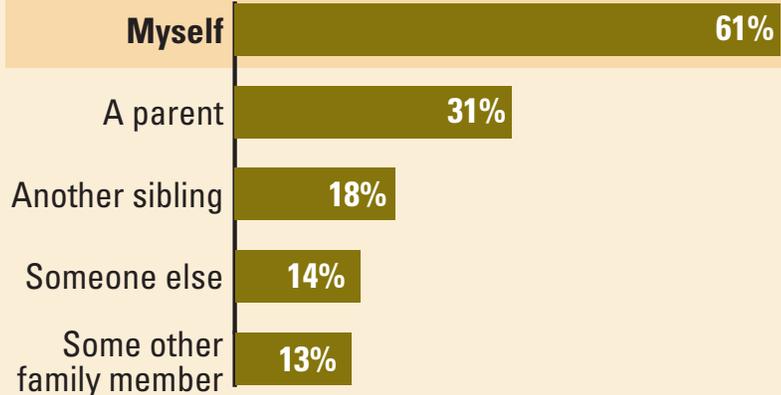


“Although I love my sister her needs are intense and ongoing, I spend at least 30% of my free time seeing to her needs. It is taxing especially as I age and know it is on my shoulders.”

The most common action that the trustee has taken is creating a special needs trust, followed by identifying alternate living arrangements should their caregiving situation change, and setting up a savings account. Less than a quarter have created a will, created a life care plan, developed an estate plan or written a letter of intent. One in ten reports that the trustee hasn't done any of these things.

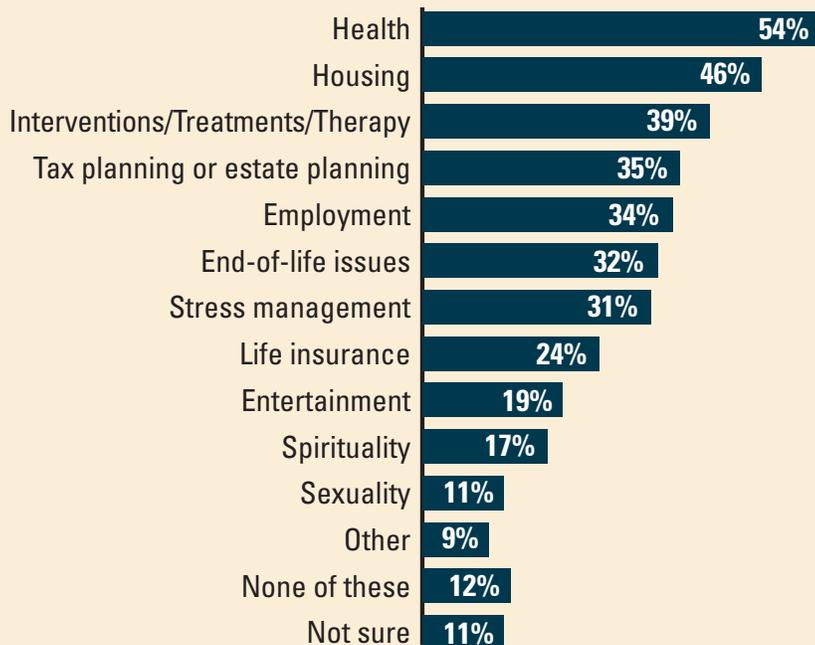
The top types of advice that respondents receive (or expect to receive) from someone who specializes in helping people with life issues related to having a sibling with special needs include health and housing, followed by interventions/treatments/therapy, tax/estate planning, and employment. Furthermore, three in ten would expect to receive advice relating to end-of-life issues and stress management.

Sibling's Future Trustee



Among those who say that a trustee will be named in the future, six in ten expect that they will be named to take on this role. Less than a third expect that a parent will be named as future trustee, and 18% say it will likely be another sibling.

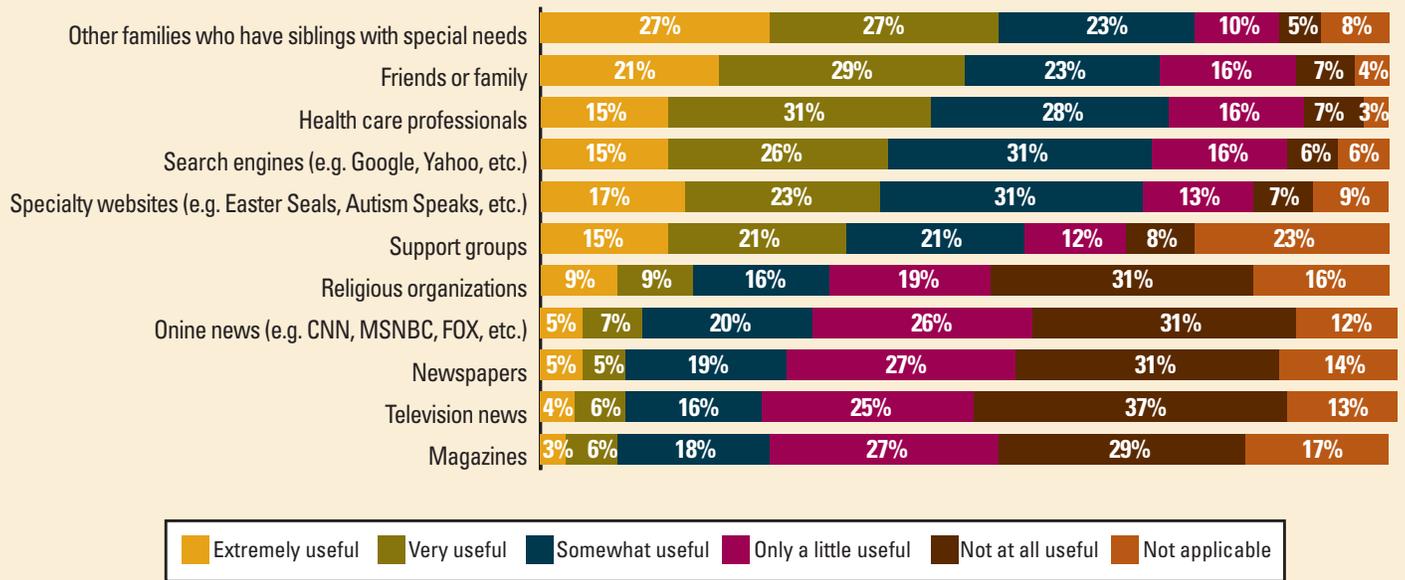
Advice Areas



"I live with concerns about how he will be taken care of if something happens to my father, and with the guilt of not being able to do more for my brother."

"The thought of my brother and his future is a burden on my life decisions now. It's a responsibility I never made a choice to have and cannot escape."

Usefulness of Information Sources



More than half of individuals with a special needs sibling find other families who have siblings with special needs as a useful source of information, followed by friends or family and health care professionals. Four in ten respondents find search engines and specialty websites to be useful sources in supporting their special needs. Few say more traditional news sources, such as online news, newspapers, TV news, and magazines are helpful in this regard.

Some might be surprised to learn that it's not professional experts who are considered the most useful sources of information, but other families who have siblings with special needs, followed by friends or family and health care professionals. The Internet has become a very helpful resource as well, whether it's a general search for a topic or a visit to a specialty website such as www.easterseals.com.

A life care plan for future peace of mind

Most siblings of adults with disabilities understand that they need a long-term plan in place. However, the study reveals that although they are concerned for the future of their brothers or sisters, they don't appear to have completed the planning necessary to ensure their care. Almost a third have done no planning at all or don't even know if any planning has been done. Some may have made a start, for example by setting up a savings account or identifying future living arrangements. However, by themselves these actions may prove ineffective.

Money put aside in a savings account, for example, may be at risk if it's in the name of a person applying for government benefits. A will might not be interpreted as its author intended without the guidance of a letter of intent. The group home, paid caregiver, or other desired future arrangement might be out of reach financially if an estate has not been funded for it. A properly-conceived Life Care Plan can help prevent these negative outcomes.

A comprehensive Life Care Plan addresses quality of life – food, clothing, shelter, health, finances, family life, entertainment, employment, retirement and more. It includes such items as a will, a letter of intent, a special needs trust, government benefits, legal and estate planning, and designation of a guardian/conservator/trustee. A Life Care Plan developed by a team of professionals working in collaboration with the family helps ensure a secure future for an individual with a disability, and provides his or her sibling and other loved ones with peace of mind.

As many as three quarters of current primary caregivers say that sometimes their relationships with their siblings put strain on their families. Some point to sacrifices their parents had to make, opportunities lost, friendships and school activities disrupted because of the demands of caregiving. A good deal of this strain is caused by financial stress. Sisters and brothers entrusted with the care of a sibling with a disability want a secure future both for them and for their own children. Having a Life Care Plan in place for future care of a sibling with a disability, which may change throughout the siblings lifetime, can ensure the best possible outcome for families in this generation and the next.

Having a Life Care Plan in place for future care of a sibling with a disability, which may change throughout the siblings lifetime, can ensure the best possible outcome for families in this generation and the next.

"Now my parents are gone and they left no primary plan of action in order for where she will live and survive."

About the research



Two Ipsos polls were conducted on behalf of MassMutual and Easter Seals:

A national survey among 1,392 adults who have a sibling 18 and older. Interviewing was conducted July 30 – August 1, 2012 via Ipsos’ online omnibus. A survey with an unweighted probability sample of this size and a 100% response rate would have an estimated margin of error of +/- 2.6 percentage points 19 times out of 20 of what the results would have been had the entire U.S. population of adults ages 18+ with an adult sibling been polled.

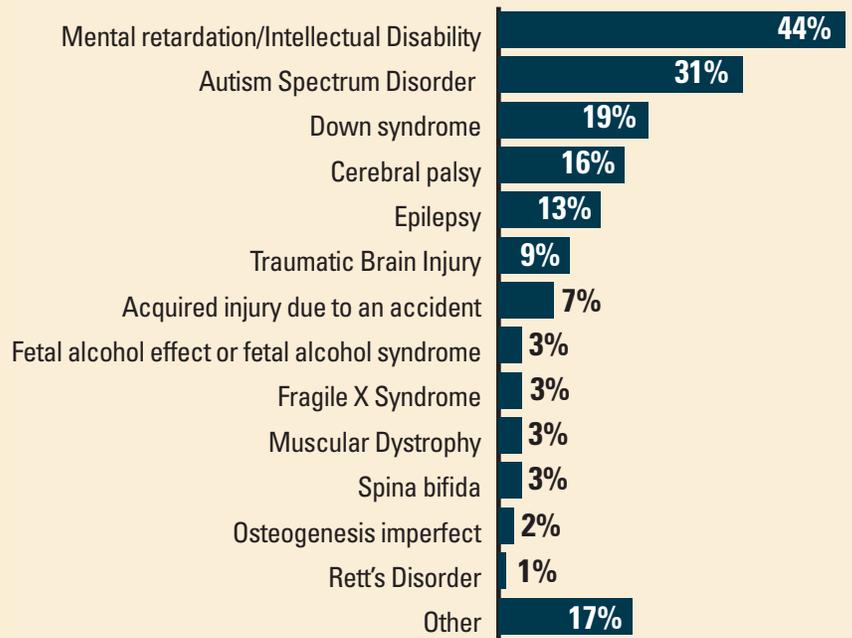
A national survey of 351 adults who have a sibling with a Developmental disability, such as Autism Spectrum Disorder, an Intellectual disability, or a Physical disability. Respondents were drawn from a variety of groups and organizations. Sample sources for this study include members of Easter Seals, the Sibling Leadership Network, the Sibling Support Project, qualified omnibus respondents, and past respondents from a survey conducted by Vanderbilt University.

Interviewing was conducted July 26th – September 17th, 2012. A survey with an unweighted probability sample of this size and a 100% response rate would have an estimated margin of error of +/- 5.2 percentage points.

All sample surveys and polls may be subject to other sources of error, including, but not limited to coverage error and measurement error.

The disabilities we included are noted in the following graph.

Specific Types of Disabilities



MassMutual SpecialCareSM

MassMutual's SpecialCare program provides access to information, specialists, and financial solutions that can help improve the quality of life for people with disabilities and other special needs, their families and caregivers. For people with physical, mental, or emotional disabilities, health issues are only the beginning. Financial concerns may also weigh heavily. Preparing for a solid financial future can help provide peace of mind for families now and when they can no longer care for their children with special needs later.

MassMutual emphasizes a "Person-Centered Life Care Planning Process," meaning that the focus of everything we do is on the person with special needs. Ultimately, the result is a Life Care Plan developed in collaboration with these families which enables the person to obtain the best quality of life possible while preserving much-needed government benefits. A Life Care Plan is a coordinated program of future care planning, financial, and legal strategies for people with disabilities and their families. To effectively create a Life Care Plan for a person with a disability, the family must work with a team of advisors – no one professional can provide everything a family needs. This team may include their banker, accountant, financial advisor, and/or MassMutual Special Care Planner or Chartered Special Needs Consultant (ChSNC), attorney, social workers, and health care providers – all working in concert to review the family's complete financial picture and offer options that make the most sense.

MassMutual's Special Care Planners/ChSNC receive advanced training in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with special needs. The Chartered Special Needs Consultant (ChSNC) program is offered by The American College in Bryn Mawr, PA, exclusively for MassMutual Financial Service Representatives.

A planning checklist for caregivers

- Create a Life Care Plan and communicate it to all interested parties.
- Create a letter of intent and update it periodically.
- Include yourself in your plan.
- Identify financial resources, including government benefits.
- Establish a special needs trust.
- Choose guardian/conservator/trustee.
- Complete estate planning.
- Review health plan options.
- Explore housing options.
- Anticipate changes.

About Easter Seals

Easter Seals is the leading non-profit provider of services for individuals with autism, developmental disabilities, physical disabilities and other special needs. For more than 90 years, we have been offering help and hope to children and adults living with disabilities, and to the families who love them. Through therapy, training, education and support services, Easter Seals creates life-changing solutions so that people with disabilities can live, learn, work and play. Support children and adults with disabilities at www.easterseals.com.

About Ipsos Public Affairs

Ipsos Public Affairs teams around the world conduct research on public policy issues and on the attitudes and behaviors of citizens and consumers. We also conduct public opinion research and elite stakeholder, corporate, and media opinion research. Our goal is to help our clients manage issues, advance reputations, determine and pinpoint shifts in attitude and opinion, and enhance communications.

We provide clients with information that helps them understand how they can build efficient and effective policies, programs, communications strategies, and marketing initiatives. For more information, please visit <http://www.ipsos.com/public-affairs>.

About MassMutual

Founded in 1851, MassMutual is a leading mutual life insurance company that is run for the benefit of its members and participating policyowners. The company has a long history of financial strength and strong performance, and although dividends are not guaranteed, MassMutual has paid dividends to eligible participating policyowners consistently since the 1860s. With whole life insurance as its foundation, MassMutual provides products to help meet the financial needs of clients, such as life insurance, disability income insurance, long term care insurance, retirement/401(k) plan services, and annuities. In addition, the company's strong and growing network of financial professionals helps clients make good financial decisions for the long-term.

MassMutual Financial Group is a marketing name for Massachusetts Mutual Life Insurance Company (MassMutual) and its affiliated companies and sales representatives. MassMutual is headquartered in Springfield, Massachusetts and its major affiliates include: Babson Capital Management LLC; Baring Asset Management Limited; Cornerstone Real Estate Advisers LLC; The First Mercantile Trust Company; MassMutual International LLC; MML Investors Services, LLC, Member FINRA and SIPC; OppenheimerFunds, Inc.; and The MassMutual Trust Company, FSB.

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