



Siblings Study

made possible by MassMutual Financial Group



Executive Summary

Easter Seals Siblings Study
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“From the time they are born, our brothers and sisters are our collaborators and co-conspirators, our role models and cautionary tales. They are our scolds, protectors, goads, tormentors, playmates, counselors, sources of envy, objects of pride. They teach us how to resolve conflicts and how not to; how to conduct friendships and when to walk away from them. Our spouses arrive comparatively late in our lives; our parents eventually leave us. Our siblings may be the only people we’ll ever know who truly qualify as partners for life.”

Excerpted from Time Magazine’s article “The New Science of Siblings,” July 2006

Siblings: Partners for Life

But what's the experience like for siblings who take on the role of caregiver for an adult sibling with a developmental, intellectual or physical disability? Or who are beginning to prepare for that time in the future when they'll step into that role? What happens to the sibling relationship? And what services and supports – financial, emotional, and otherwise – do they need?

Of the 65 million caregivers in the United States today*, we know many are the primary care provider for an adult brother or sister. Yet far more attention is typically paid to caregivers in the role of spouse, parent or adult child. We don't hear much about the sibling caregiver.

As one of the nation's leading nonprofit provider of services for people living with disabilities, Easter Seals realizes the important role adult siblings play in the lives of their loved ones with disabilities, many assuming primary care for their brother or sister at some point during their sibling's lifetime.

That's why we conducted our *Easter Seals Siblings Study* – to call attention to the experiences of caregivers as well as the services and supports families need. It provides Easter Seals an opportunity to advocate on their behalf and make sure sibling caregivers and adults living with disabilities can access the resources they need to live, learn, work and play in their communities. Easter Seals objective in fielding the Siblings Study was to reach out to sibling caregivers and future caregivers to better understand the implications of taking on this role, as well as contrast attitudes and perceptions of these sibling relationships with those of the general public. Thus, the research was two-fold:

- A more in-depth view of adults who have siblings with a developmental disability
- A parallel, shorter survey among adults in the general population who have a sibling without a disability

Easter Seals thanks [MassMutual](#) for making the Easter Seals Sibling Study possible. As an Easter Seals national corporate partner, MassMutual is committed to serving children and adults with disabilities through its exclusive SpecialCareSM program, a solution that gives families living with autism and other disabilities access to information, specialists, and financial strategies that can help improve their quality of life. [Learn more about SpecialCare here.](#)

Easter Seals will use these findings to raise awareness of and advocate for the life-long services and supports families and caregivers desperately need—working to lessen disparities and bridge the gap for people living with developmental disabilities across the country.

Key Findings & Takeaways

By and large, most respondents convey their sibling with a disability had a positive and unique impact on their life – and even the lives of their own children. But, they have also experienced the very real, often challenging negative effects of caregiving, particularly from an emotional and financial perspective.

Many adult siblings are already the primary caregiver for their sister or brother with a disability. Many who aren't yet in a caregiving role expect to take on this role in the future. Yet future caregivers don't feel prepared for the demands of this role, especially when it comes to financial considerations.

And, many siblings aren't taking advantage of the various resources and support groups available to them. Such supports would likely help them better care for their sibling, while juggling their own needs and those of other family members.

Level of Involvement

- Six in ten respondents say they are involved in their sibling's day-to-day life; less than three in ten of the general public respondents say the same.
- Respondents have siblings with an array of disabilities (most commonly an intellectual disability), and report their siblings have various levels of independence.
- Nearly half say their parents currently house and provide caregiving for their sibling with a disability, another 14% say their sibling lives with them and still 23% say they are already the primary caregiver.
- Three quarters of primary caregivers say caring for their sibling is a full-time job, and 30% say they don't receive support – emotional, physical and financial help – from other friends and family.
- Nearly a third of respondents expect to take on the role of primary caregiver in the future. And these future caregivers may be overestimating how much support they will get from other family and friends.
 - Among them, eight in ten say they are comfortable taking on this role, but they are much more likely to say they are emotionally prepared than financially prepared (60% vs. 33%).
 - While more than two thirds (67%) of future caregivers expect to receive emotional, physical and financial help, only 58% of current caregivers say they actually receive this support.
 - Future caregivers are also less likely than current caregivers to see caregiving as a full-time job (55% vs. 75%).



Family Dynamics

- Roughly 80% say they have a close relationship with their sibling with a disability and that this relationship enhances their life; while just 60% of the general public respondents feel the same way about their sibling.
- Approximately 60% say having a sibling with a disability has a positive impact on their quality of life – teaching them patience, understanding, compassion, and providing perspective.
 - This feeling trickles down to the children of the caregiver, too, as four in ten respondents say their kids benefit from having their sibling with a disability (or aunt/uncle) in their lives.
- Respondents also express negative effects as well.
 - At least one in five say having a sibling with a developmental disability 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 life.

- 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.
- Three quarters of primary caregivers say sometimes their relationship with their sibling puts a strain on their family life and that it's difficult to balance their own needs and those of their family with those of their sibling.

Financial Implications

- Over a third say they provide their sibling with financial support, most commonly those serving as the primary caregiver (81%), those providing housing for their sibling (82%), men (54%) and those 55 and older (43%).
- Two in five respondents say taking care of their sibling with a disability has caused a lot of financial stress for their family.
- 60% 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 with a disability needs.
 - Those who expect to take over as primary caregiver are even more likely to have these concerns.
 - Similarly, a majority of future caregivers say that they don't feel they are financially prepared to take over this role.
- Just over half of respondents have named a trustee to oversee their sibling's finances, most commonly the respondent themselves (49%), followed by a parent (39%).

Resources & Support

- Respondents are most likely to say other families who have siblings with disabilities are a useful source of information, as well as friends, family and health care professionals.
- Less than a third of respondents are currently involved in a support group, though nearly half say that they would like to know more about local or online support groups.
- While nearly six in ten respondents are aware of people/organizations who specialize in supporting caregivers and siblings with disabilities deal with life issues, just a third report they utilize these services.
 - Those who are unaware of these services are more likely to say having a sibling with a developmental disability has a negative impact on their quality of life, their relationship with their parents, their interactions with their extended family, and their interactions with friends and acquaintances.
 - The top areas of advice respondents receive (or expect to receive) from these support specialists are health and housing, followed by interventions/treatments/therapy, tax/estate planning, and employment.

Methodology

Ipsos conducted two polls on behalf of Easter Seals and the study's sponsor, MassMutual Financial Group:

- A national survey among 1,392 adults age 18 and older who have an adult sibling. Ipsos conducted interviews between July 30 and 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, including autism, an intellectual disability or a physical disability. Respondents were drawn from a variety of groups and organizations, including Easter Seals, the Sibling Leadership Network, and the Sibling Support Project. Ipsos conducted interviews between July 26 and September 17, 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.



"Because of Mary, I have greater empathy and a purer childlike joy for the little things in life. I smile more because of my sister, and I never fail to smile when I'm with her." –Joseph

** More than 65 million people, 29% 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.*

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