Understanding the long-term challenges of disability

Easter Seals “Living with Disabilities” study
Made possible by MassMutual
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Over 20 million American families today have at least one member with a disability.\(^1\) Government, non-profits, and the private sector have put into place many services to aid them. However, while awareness and appreciation of the diversity of our population is growing, the day-to-day struggles of these families often go unrecognized by others.

Advances in science, technology, and medicine mean that millions of children with disabilities are now living to adulthood. With this progress come new challenges. How can the basic needs of this growing population be met? And how can families help ensure that, once those basic needs are filled, their adult children may enjoy the highest possible quality of life?

In order to better understand the unique issues faced by adults with disabilities and by their parents and caregivers, the Easter Seals *Living with Disabilities* study, sponsored by Massachusetts Mutual Life Insurance Company (MassMutual), was conducted by Harris Interactive, one of the leading consumer research companies in the U.S. The study reveals that families have far-ranging concerns and may be overwhelmed about the future of their children with disabilities. This key findings overview highlights some primary issues that families are facing and focuses on the many challenges related to life care planning.

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Quality of life concerns
For families of adult children with disabilities, simply getting through each day may be a struggle. More than a third of these adult children need support with daily activities such as bathing, dressing, and eating. About three out of four need help shopping and preparing meals; four out of five need help getting places. Twice as many stay at home during a typical work week compared to adult children without disabilities. Yet over nine out of ten parents of adult children with disabilities receive little or no financial support, eight out of ten receive little or no physical support, and almost half receive little or no emotional support from extended family or friends.

Most support from family or friends is emotional support, though only a quarter of families with disabled children report receiving a great deal or a lot of support emotionally.
Parents of adult children without disabilities generally describe their offspring as having received an education which has adequately prepared them for life. Most agree their children have friends, a place to live, a paying job, recreation, exercise, and financial independence. Parents of adult children with disabilities have vastly different responses. In every single category, they express concern for specifics such as health and employment, as well as intangibles such as quality of life.

“My other children are very grounded, rational people who have chosen to work in fields that are disability related. They work with me as advocates for other families. My husband has taken on various roles that he may not have otherwise if we did not have a child with a disability. We are a united family with very strong ties.”
Despite the challenges, 42 percent of parents say that having an adult child with a disability has made the family more cohesive. In an unaided question, many stressed the benefits of raising and caring for a child with a disability through adulthood: qualities such as increased patience, respect, acceptance of others, advocacy, and appreciation of life to the fullest.
Financial concerns

Day-to-day concerns are critical for families of adult children with disabilities, yet the long-term financial future may be even more distressing. Approximately half of the parents reported that the cost of caring for their son or daughter had negatively impacted their ability to save for emergencies, to take family vacations, and to save for retirement. Simple luxuries that most Americans occasionally enjoy, such as eating in a restaurant, are out of the picture for them. Frequently they have had to deny their other children extracurricular activities or even education. In many cases, the American dream of home ownership has been out of reach.

“I have not worked full-time in 20 years because of his disability. This has impacted our family financial health. I often put off ‘want to do’ things to take care of him.”

Financial concerns of parents of adult child with disability…

- Save for emergencies: 51% (very/somewhat negatively impacted), 5% (very/somewhat positively impacted)
- Take family vacations: 50% (very/somewhat negatively impacted), 6% (very/somewhat positively impacted)
- Save for retirement: 49% (very/somewhat negatively impacted), 3% (very/somewhat positively impacted)
- Eat at restaurants: 35% (very/somewhat negatively impacted), 5% (very/somewhat positively impacted)
- Pay for education for other children: 28% (very/somewhat negatively impacted), 4% (very/somewhat positively impacted)
- Pay for extracurricular activities for other children: 27% (very/somewhat negatively impacted), 7% (very/somewhat positively impacted)
- Buy a house: 23% (very/somewhat negatively impacted), 7% (very/somewhat positively impacted)
A majority of parents of adults with disabilities have multiple fears for their children after their deaths, whereas a strong majority of parents of adults without disabilities cite no such fears. Parents of adults with disabilities worry about their children’s living situations, their emotional stability, and their quality of life. They worry about their finances and their ability to support themselves and to afford medical care. Most parents of adults with disabilities feel their son or daughter is somewhat or very unprepared for the future.

“\textit{I put off retirement, travel, vacations, relationships, social events at night, professional development, events, home ownership...financial, emotional, physical well-being. There is no me left!}”

“\textit{There is no money in savings because of paying for private school educations. We will never be able to retire.}”
Employment

One of the biggest measures of preparedness for the future is employment. Work means self-reliance, social interaction, and of course a paycheck. Most adults who don’t have disabilities work either full or part time, the study shows.

On the other hand, less than a third of adults with disabilities work. They may spend a portion of each day in school, volunteering, or attending a day program. Most adults with disabilities, who don’t work, however, stay at home all day.

Employment of adults with disability vs. adults without disability

28% have received a Certificate of Completion – a non-high school diploma

Adult with disability

- Employed full time: 30%
- Employed part time: 19%
- Self-employed: 11%
- Not employed, but looking for work: 22%
- Not employed, unable to work due to disability: 16%
- Retired: 11%
- Stay-at-home spouse: 2%

Adult without disability

- Employed full time: 48%
- Employed part time: 24%
- Self-employed: 11%
- Not employed, not looking for work: 11%
- Not employed, unable to work due to disability: 11%
- Retired: 3%
- Stay-at-home spouse: 1%
Independent living

“Home” for adult children with disabilities is most often with parents or a guardian. Only about one in six lives independently. What will happen to these children when their parents are no longer there to care for them?

- 90% of adult children with a disability are 18-34 years old
- 91% of adult children without a disability are 18-34 years old

Over half of parents of adults with disabilities do not utilize services which specialize in assisting with issues related to their son/daughter’s disability. Among those parents of adults with disabilities who utilize specialty services, half receive advice on health issues.

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<tr>
<th>% of Parents with an adult child with a disability who receive advice on health issues</th>
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<tr>
<td>55% No</td>
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<tr>
<th>% of Parents with an adult child with a disability who receive advice on health issues</th>
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<tbody>
<tr>
<td>Health - 49%</td>
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<tr>
<td>Employment - 36%</td>
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<td>Interventions/treatments - 36%</td>
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<tr>
<td>Emotions - 33%</td>
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<td>Finances - 30%</td>
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<td>Tax/estate planning - 29%</td>
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<td>Stress management - 24%</td>
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<tr>
<td>Spirituality - 22%</td>
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<tr>
<td>Shelter - 21%</td>
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<tr>
<td>Family life - 18%</td>
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<tr>
<td>Diet - 17%</td>
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<td>Life insurance - 11%</td>
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<td>Entertainment - 10%</td>
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<td>Retirement - 9%</td>
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<tr>
<td>Sexuality - 6%</td>
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<tr>
<td>End-of-life issues - 5%</td>
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<tr>
<td>Clothing - 4%</td>
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<tr>
<td>Other - 12%</td>
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<tr>
<td>Not sure - 8%</td>
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- 45% Yes
- 55% No
Getting a life care plan in place

Most families of children with disabilities understand that they need a long-term financial plan in place. However, although they are concerned for the future of their adult children with disabilities, they don’t appear to have completed the planning necessary to ensure their care. Such planning is difficult and confusing for many families. They may have put money aside or secured government assistance, but all of that could be at risk if proper planning is not done.

The study reveals that only a tiny fraction of these parents have a Life Care Plan in place. About a third have done no planning at all for their adult children with disabilities. Some may have taken a few steps toward the time when they can no longer be with their children. They may, for example, have created a will or designated a guardian. However, without a good understanding of the total picture, these steps may be ineffective.

A large number of those parents of adults with a disability who have created a will, for example, have not included their adult son or daughter in that will. If they have included them, might this action create a tax burden, or render their child ineligible for government benefits? Guardianship is another complex issue. The study reveals that over 40 percent of adult children with disabilities have no guardian at all. If they do, it is in most cases a parent. Who will assume responsibility for that adult child when the parent is gone? What is really needed is a comprehensive Life Care Plan.
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 adult child with special needs, and provides his or her family with peace of mind.

Of disabled adult children who have a guardian (41% do not) that guardian is most likely their parent.
Impact on the family

As stark as some of this information may be, at the heart of the study are real people and real families with a belief that, “we’re stronger together.” When asked if their life had been negatively or positively impacted by their child’s disability, many parents felt raising a child with a disability through adulthood is a balance of the two:

- While half of parents of adult children with disabilities report being negatively impacted by their child’s disability, 30% say their quality of life has been positively impacted.
- Parents of adult children with disabilities rate their child’s quality of life lower (61%) than parents of children without disabilities (82%), but the majority still say it’s excellent or good.
- Older parents of adult children with disabilities are less likely to rate their child's quality of life as excellent or good than younger parents – age of parents 35-44: 79%; age of parents 45-54: 60%; and age of parents 55+: 58%.

And, contrary to popular belief, family cohesiveness is one of the areas most positively impacted by having an adult child with a disability. Parents say having an adult child with a disability has positively affected: the cohesiveness of my family (42%), the relationship with my partner/spouse (32%), and the relationship with my other children (30%).

Planning for the future is a complex and daunting task for any family, particularly one faced with the special challenges which come with disability. These families can draw upon the unique strengths so clearly highlighted by this study.

Many parents feel that having a child with a disability has made the family more cohesive. Relationships within the family are often stronger. Outside of the family, interactions with friends, acquaintances, and extended family members have been positively affected in many cases. Caring for their children has often increased their patience, their awareness, their advocacy, their faith. With those strengths and the necessary tools, parents of adults with disabilities can fashion the best possible future for their children, and thereby leave a legacy of love.

- Positive affects

  - Patience: 20%
  - Respect/acceptance of others: 18%
  - Made me aware/knowledgeable: 14%
  - Appreciate life/live life to the fullest: 13%
  - Empathy/compassion: 11%
  - Became an advocate for people: 11%
  - He/she is a wonderful person: 10%
  - Met others who have experienced: 8%
  - He/she is a loving person: 7%
  - Bonding/family became closer: 5%
  - Made us/me strong: 4%
  - Increased my faith in God: 4%
  - I am a better person: 4%
  - Other: 4%
  - None/nothing: 3%
  - Don’t know: 20%
To qualify for the study, the adult child or adult with a disability had to have developed his or her disability prior to age 22. The disabilities we included are below:

- Acquired injury due to an accident
- Asperger’s Disorder
- Autism/Autistic Disorder
- Blind/vision loss
- Cerebral palsy
- Childhood Disintegrative Disorder
- Deaf/hard of hearing
- Down syndrome
- Epilepsy
- Fetal alcohol effect or fetal alcohol syndrome
- Fragile X Syndrome
- Mental retardation
- Muscular Dystrophy
- Osteogenesis imperfecta
- Pervasive Developmental Disorder
- Psychiatric disabilities
- Rett’s Disorder
- Spina bifida
- Traumatic brain injury

About the research

The Easter Seals’ Living with Disabilities study was conducted online within the United States by Harris Interactive on behalf of Easter Seals between August 18, 2010 and September 13, 2010 among 1,714 adults over the age of 18. Of the total, respondents were segmented into one of three separate groups: 390 adults living with a developmental disability over the age of 18, 318 parents of adult children over the age of 18 who have developmental disabilities, and 1,006 parents of adult children over the age of 18 without disabilities.

Using the Harris Poll sample, as well as a sample provided by Easter Seals and other organizations including the Autism Society of America, National Council on Independent Living, American Association of People with Disabilities, and Justice for All, study participants were queried about daily life, employment, finances, transportation, housing, independence, relationships, recreation, education, and healthcare. No estimates of theoretical sampling error can be calculated; a full methodology is available.
MassMutual SpecialCare℠

MassMutual’s SpecialCare program provides access to information, specialists, and financial products and services 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 helps to enable the person to obtain the best quality of life 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 other financial professional that specializes in working with special needs, 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 receive advanced training and information in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with special needs. The certificate program is offered by The American College in Bryn Mawr, PA, exclusively for MassMutual financial professionals.

A planning checklist for parents and 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.
- Anticipate changes when your child reaches the age of majority.
- Explore housing options for when your child becomes an adult.
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. Visit www.easterseals.com.

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Harris Interactive is one of the world’s leading custom market research firms, leveraging research, technology, and business acumen to transform relevant insight into actionable foresight. Known widely for the Harris Poll and for pioneering innovative research methodologies, Harris offers expertise in a wide range of industries including healthcare, technology, public affairs, energy, telecommunications, financial services, insurance, media, retail, restaurant, and consumer package goods. Serving clients in over 215 countries and territories through our North American, European, and Asian offices and a network of independent market research firms, Harris specializes in delivering research solutions that help us – and our clients – stay ahead of what’s next. For more information, please visit www.harrisinteractive.com.
About MassMutual

Founded in 1851, MassMutual is a leading mutual life insurance company that is run for the benefit of its members and participating policyholders. 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 policyholders every year 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, member FINRA and SIPC; OppenheimerFunds, Inc.; and The MassMutual Trust Company, FSB.

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