

An Overview of Key Findings  
for Consumers

# Understanding what it means to live with autism



Easter Seals' "Living with Autism" study

Made possible by MassMutual



We'll help you get there.™



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Autism Spectrum Disorders (ASD) affect nearly one in 150 children,<sup>1</sup> and present an evolving set of educational, health and financial challenges for their families. With Harris Interactive, Easter Seals and Massachusetts Mutual Life Insurance Company (MassMutual) have undertaken a comprehensive study of these issues that clearly shows that families have far-ranging concerns and can be overwhelmed about the future of their children with ASD. This key findings overview of the Easter Seals' "Living with Autism" study highlights some primary issues that families are facing and focuses on the many challenges related to life care planning.

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<sup>1</sup> Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, Six Site, United States, 2000. Surveillance Summaries, February 9, 2007. MMWR 2007; 56 (No. SS-1)

## Background and methodology

Autism Spectrum Disorders (ASD) are some of the most complex disabilities that families can face. The U.S. Centers for Disease Control and Prevention estimate that ASD is now found in as many as one in 150 children — with males four times more likely to have autism than females. But even as we continue to gain a greater understanding of ASD and its daily presence in the lives of millions of families, there's little information on how ASD is affecting them. It's a knowledge gap that inhibits government, non-profits, and the private sector from optimizing their services and assistance to families struggling with ASD.

Aiming to call greater attention to the ongoing and sometimes critical lifetime challenges of people living with autism, Harris Interactive, one of the leading consumer research companies in the U.S., conducted the “Living with Autism” study on behalf of Easter Seals, which MassMutual sponsored. The study consisted of a 100-question multiple-choice online survey that was completed by 1,652 parents of children with ASD aged 30 or younger. An additional 917 parents of children without any special needs age 30 or younger also completed surveys and were included as a point of reference and comparison. The surveys were completed between June 16 and July 17, 2008, and the data was demographically weighted to achieve a representation of the U.S. population. No estimates of theoretical sampling error can be calculated; a full methodology is available. Study participants were not provided with information about who commissioned the study.

For more information and a link to the full research results, visit [www.massmutual.com/autism](http://www.massmutual.com/autism).



### **There are 5 diagnostic classifications of ASD:**

- Autistic Disorder
- Asperger's Syndrome
- Pervasive Developmental Disorder
- Rett's Disorder
- Childhood Disintegrative Disorder

# Independence and ASD: a worry that never fades

## Top concerns parents have for children under 18 with ASD

- Independence
- Financial well-being
- Quality of life
- Employment
- Housing needs
- Education
- Health
- Longevity of life

In addition to the many financial challenges that families with ASD must respond to, the study gives voice to many other quality-of-life concerns. The day-to-day routine of these families can be a time-consuming, tiring process. For instance, it can take children with ASD significantly more time to accomplish basic personal hygiene to get ready for each day and prepare for bed — nearly an hour at the beginning of the day and more than three-quarters of an hour each evening. For many families with ASD facing these basic challenges, the notion of long-term independence can be frustratingly elusive.

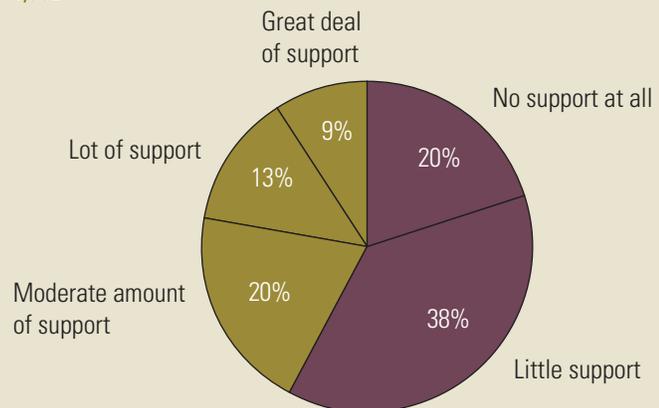
For parents of children with ASD, there's an emotional component to the challenge as well. Too often, families must cope with ASD on their own, with little support from extended family and relatives.

From an educational perspective, children with ASD typically do not attend mainstream classes and function at a lower educational level than other children their age. Math and literacy skills are below grade-level even though they are promoted from grade to grade. This weaker educational foundation could carry implications for the lifetime financial and social picture.

## Amount of support from extended family and friends

### Parents of children with ASD

N=1,652





Looking further into the future, few parents believe their children with autism will be able to make their own life decisions, establish friendships, have a spouse, be valued in the community, participate in age-appropriate activities and recreation, or develop strong religious affiliations. In particular, less than 40 percent of parents have set up bank accounts for their children (compared to 55 percent of typical children). Only 9 percent of children have a cell phone and only 1 percent own a credit card.

About only 20 percent of 16-year-olds with ASD have looked for employment (compared to 75 percent of typical teenagers). That gives rise to parental concern about their children’s ability to find paid work and access to transportation.

Collectively, these factors all have a bearing on the short- and long-term financial situation for families of children with ASD.

| <b>Person who first made diagnosis of ASD</b> |      |
|---|------|
| Psychologist                                  | 26%  |
| Developmental pediatrician                    | 23%  |
| Neurologist                                   | 16%  |
| Psychiatrist                                  | 10%  |
| Other   | 9%   |
| Pediatrician                                  | 8%   |
| Teacher                                       | 6%   |
| General practitioner                          | < 1% |
| N=1,652                                       |      |

# The not-so-hidden worry: family finances

It's sometimes difficult to imagine or recognize the isolation and strain that many families with children with ASD feel if you're not directly affected or dealing with the same challenges on a daily basis. But – from education and health care to shelter and daily living skills – the long-term worries are real and extensive.

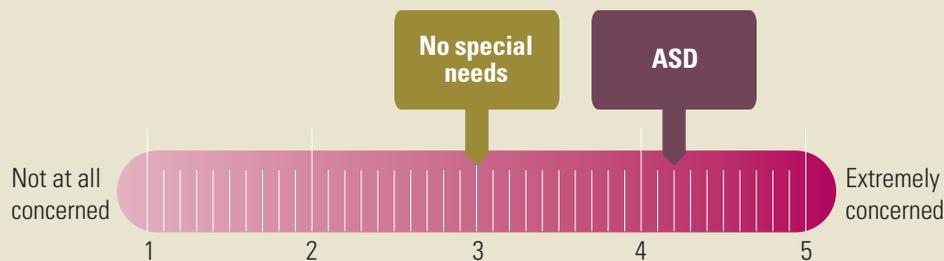
While obtaining proper care and services for their children are always uppermost in the minds of virtually all families, most report that the financial future is another major worry — and with good reason. The rising cost of caring for

children with ASD is creating extraordinary demands on family financial resources. Their needs are great and the complexity of the challenge is much greater than that faced by other families.

Forty-seven percent of parents worry that this drain will financially impact their ability to raise other siblings and more than half report that they are concerned that these costs will severely hamper retirement plans. Nearly three quarters are worried about their children's financial future after they are no longer able to care for them.

## Concerned with child's future financial well-being

Parents of children with...



Parents of children with ASD (N=1,652)  
Parents of children with no special needs (N=917)

Financial concerns are higher among parents living with ASD than typical parents.

Parents of children with ASD are significantly more likely to have incurred additional debt to meet their families' needs than parents with children without disabilities. Regardless of the type of ASD, health insurers "always or often" pay for services only 39 percent of the time. Despite these meaningful and legitimate financial concerns, only about half of these families have consulted with a financial adviser or professional to develop or implement strategies. This is roughly the same rate found in families without special needs.

### Parents of children with ASD:

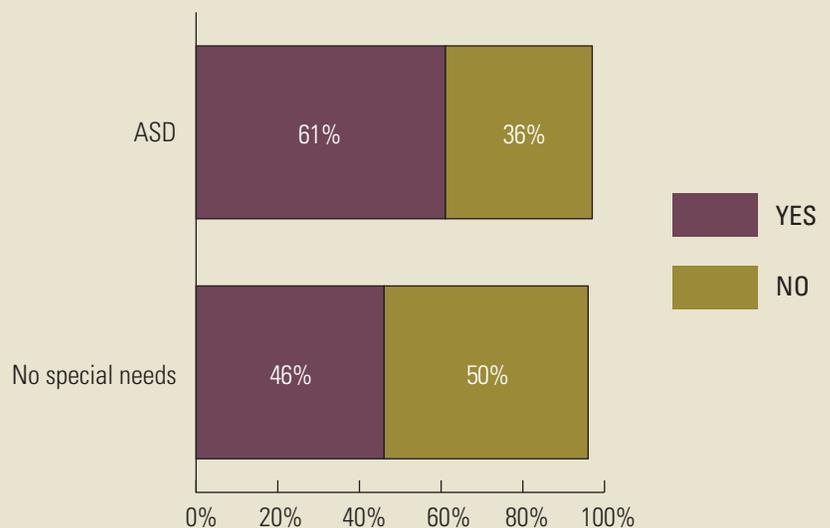
- **4x** more likely to fear their child will not have enough financial support after the parents die.
- More than **3x** more likely to fear that caring for a child will cause their own retirement shortfall.
- More than **3x** more likely to say the cost of current care is draining their current financial resources.
- **5x** more likely to say the cost of care will drain their future financial resources.

## Percentage of parents who incurred debt to meet family needs

Parents of children with ASD are significantly more likely than typical parents to have incurred debt to meet their families' needs.

Parents of children with ASD (N=1,652)  
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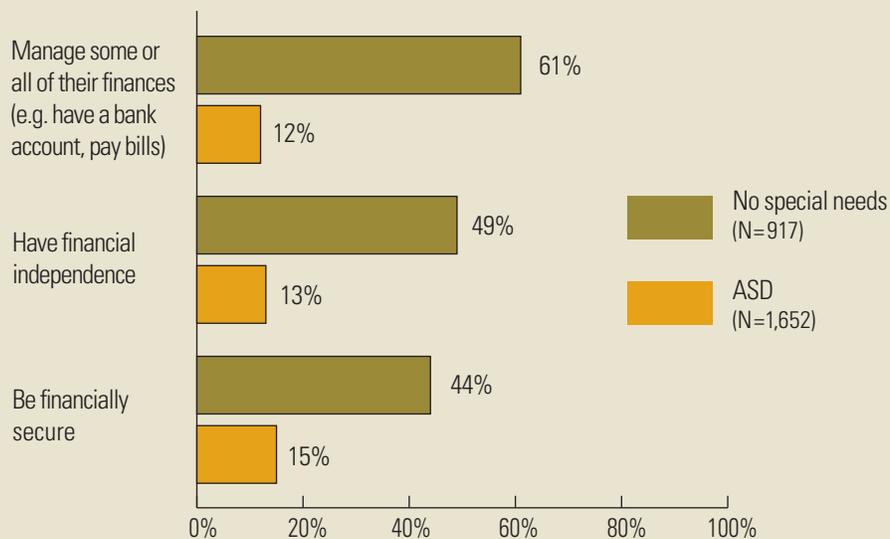
### Parents of children with...



# Getting a Life Care Plan in place

## Percentage of parents who strongly agree with statements

### My child will...



Parents of children with ASD are almost four times more likely than typical parents to feel their children will not have financial independence. Only 12% feel their children will be able to handle their day-to-day finances.

Parents of children with ASD are, by and large, realists. They understand they will have to continue to care financially for their child. According to the study, they are almost four times more likely than other parents to believe that their children will not have financial independence. Only 12 percent feel that their children will be able to feasibly manage their own day-to-day finances.

Unfortunately, even though they recognize the need for a long-term plan, many families are overwhelmed by the challenge. Parents report that integrated life care planning is hard to find and confusing.

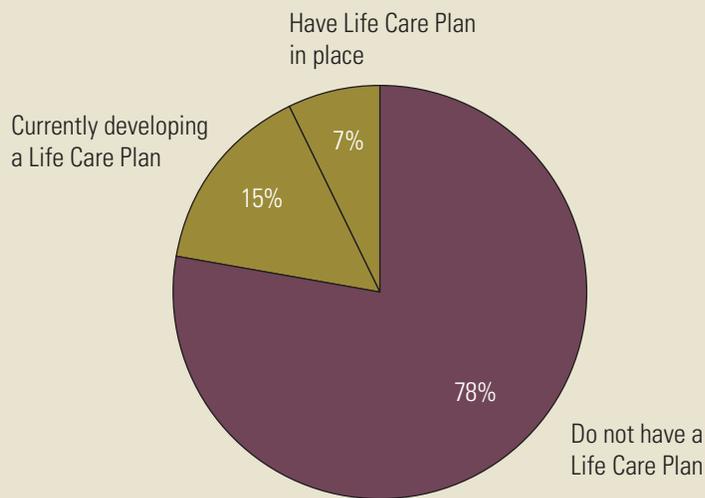
For instance, the study found that only about 40 percent of parents of children with ASD have designated a guardian or have created a will. Less than 20 percent have created a special needs trust. In fact, one-quarter of all these families have taken no planning steps at all and over three-quarters do not have a Life Care Plan. Many families are looking for expert, trustworthy help — but most (73 percent) are simply working with other family members to attempt to address the situation.

Ideally, families should devise a comprehensive Life Care Plan that encompasses basic needs and strategies for achieving the best short- and long-term quality of life in every area — food, clothing, shelter, health, finances, family life, entertainment, employment, retirement and more.

However, an overwhelming number of parents of children with ASD – 78 percent – do not have a Life Care Plan for their children, and 70 percent of all parents do not use a professional to help develop one — in fact, more than half (56 percent) do not know of any financial professional who deals with these types of life issues. Forty percent of families receive financial assistance from the government – such as Medicaid, SSI, or SSDI – but that aid could be at risk if a proper Life Care Plan isn't in place.

The good news is that those families who are designing and documenting Life Care Plans are also building in sensible financial components. Nearly 85 percent of those plans include a financial component and life insurance policies are in place in half of the households with children who have special needs.

### Percentage of parents who have a life plan in place for their children



Parents of children with ASD (N=1,652)

Most parents of children with ASD do not have a Life Care Plan for their children. Developing a Life Care Plan requires individuals to look inward and forward – imagining the hopes and dreams they want for themselves and their family with special needs – and taking action to help make it happen.

# MassMutual SpecialCare<sup>SM</sup>

## 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.

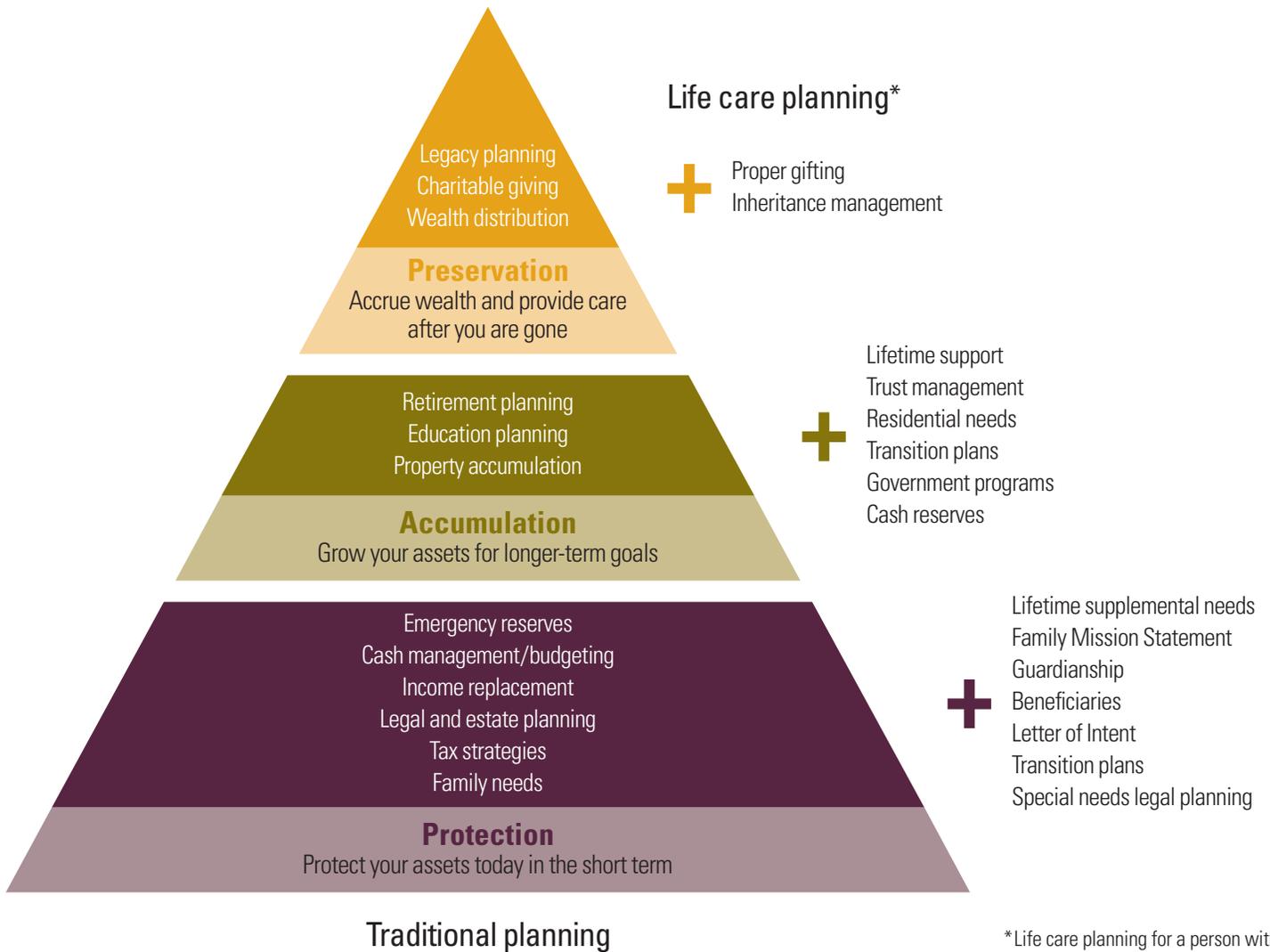
MassMutual's SpecialCare program provides access to information, specialists, and financial solutions that can help improve the quality of life for people with disabilities and other special needs, their families and caregivers. For people with physical, mental, or emotional disabilities including ASD, health issues are only the beginning. Financial concerns can 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 that enables 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 advisers — no one professional can provide everything a family needs. This team may include their banker, accountant, financial adviser and/or MassMutual Special Care Planner, 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 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 Service Representatives.

# Life Care Planning Pyramid

The Life Care Planning Pyramid below illustrates the complexities that planning for a secure financial future can entail for a person with a disability or other special need.



\* Life care planning for a person with a disability or other special need encompasses a broader range of activities and needs than traditional planning.

## **MassMutual. We'll help you get there.<sup>SM</sup>**

### **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 nearly 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](http://www.easterseals.com) or [www.actforautism.org](http://www.actforautism.org).

### **About Harris Interactive®**

Harris Interactive is a global leader in custom market research. With a long and rich history in multimodal research that is powered by our science and technology, we assist clients in achieving business results. Harris Interactive serves clients globally through our North American, European and Asian offices and a network of independent market research firms. For more information, please visit [www.harrisinteractive.com](http://www.harrisinteractive.com).

### **About MassMutual Financial Group**

MassMutual Financial Group is a marketing name for Massachusetts Mutual Life Insurance Company (MassMutual) and its affiliated companies and sales representatives. MassMutual and its subsidiaries had more than \$500 billion in assets under management at year-end 2007. Assets under management include assets and certain external investment funds managed by MassMutual's subsidiaries. Founded in 1851, MassMutual is a mutually owned financial protection, accumulation and income management company headquartered in Springfield, Mass. MassMutual's major affiliates include: OppenheimerFunds, Inc.; Babson Capital Management LLC; Baring Asset Management Limited; Cornerstone Real Estate Advisers LLC; The First Mercantile Trust Company; MML Investors Services, Inc., member FINRA and SIPC ([www.finra.org](http://www.finra.org) and [www.sipc.org](http://www.sipc.org)); MassMutual International LLC and The MassMutual Trust Company, FSB.



**MassMutual has carried the Exceptional Parent (EP) Symbol of Excellence since receiving it in 2004 in recognition of its commitment and service to people with disabilities and other special needs and their families.**

**Harris Interactive conducted the Living with Autism study on behalf of Easter Seals, which Massachusetts Mutual Life Insurance Company (MassMutual) sponsored. Study participants were not provided with information about who commissioned the study.**

