



# Key Findings Easter Seals' *Living with Autism Study*



Worry, concern, apprehension, anxiety, lost sleep, fret, uneasiness – universal feelings every parent encounters when it comes to caring for their children. Imagine life as a parent of a child with autism and how such feelings compare and, very likely, compound. What fears do families have for their children's future? What supports do they need to better cope, plan and live with autism?

The ***Easter Seals' Living with Autism Study***, made possible by MassMutual Financial Group and conducted in cooperation with the Autism Society of America, provides new insight into the ongoing challenges facing individuals and families living with autism, particularly their concerns about the future. For the study, Harris Interactive surveyed 1,652 parents of children who have autism and 917 parents of typically developing children about daily life, relationships, independence, education, housing, employment, finances and healthcare.

A new Easter Seals study closely considers and quantifies just that. The following details overall results and key findings, and offers a sampling of the powerful sentiments parents of children with autism shared with Easter Seals for the *Living with Autism Study*.

## Parents Hope for Independence

***"What will happen to my son when we are gone? Who will care for him, how will he live, who will make sure he is taken care of? He is completely dependent on us."***

For typical parents, their concerns for their children's futures decrease as their children reach adulthood. However, for parents of children with autism, their levels of concern remain high.

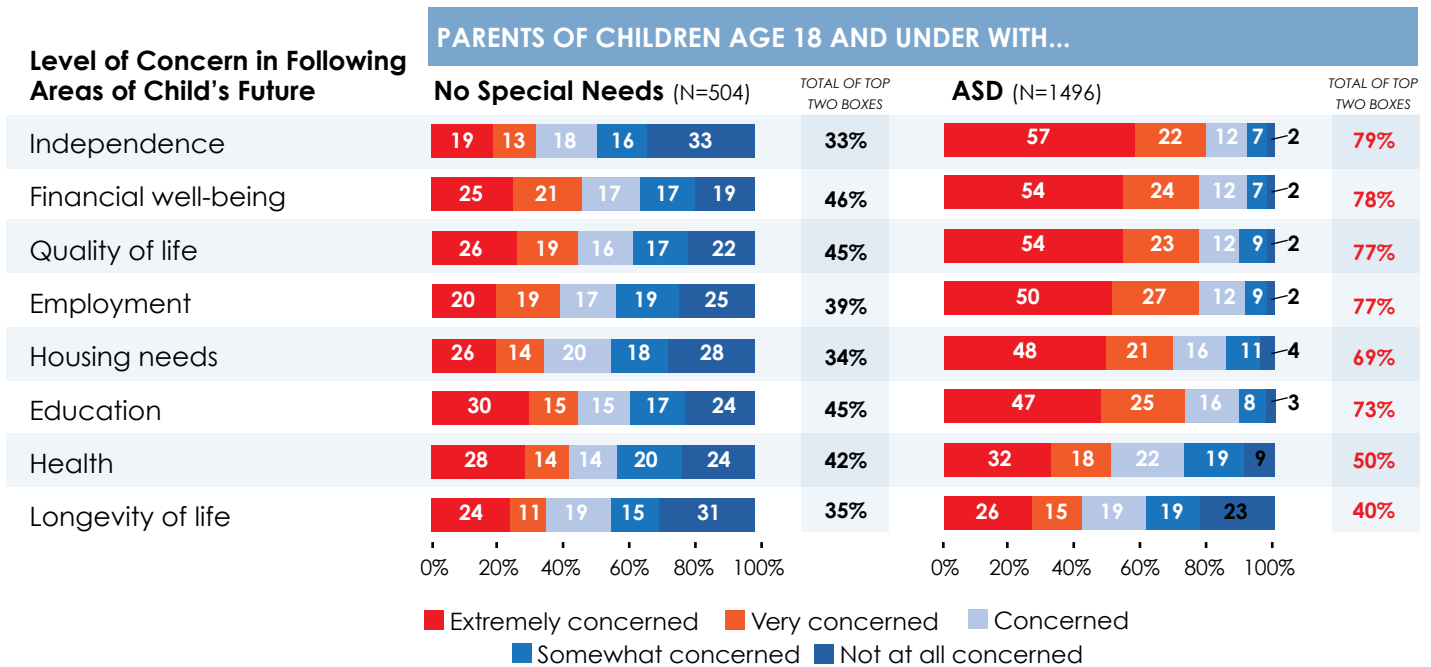
Only **28% of typical parents** are extremely or very concerned about their children's future independence; whereas **79% of parents of children with autism** are extremely or very concerned.

**The exception seems to be with parents of children with Asperger's.** In general, they are less likely to be as concerned about their children's independence, quality of life, employment, housing, health, and education as other parents of children with autism.



# Concern for Child's Future

"How concerned are you for [your] child's future as an adult in regards to each of the following areas?"



**"Can children with autism grow into independent adults who are able to live by themselves and care for themselves, work and even form relationships? What can I expect in the future for my child?"**

Parents of children living with autism are very concerned about their children fitting into society. In fact, few feel their child with autism will be able to:

- Make his or her own life decisions** (14% compared to 65% of typical parents)
- Have friends in the community** (17% compared to 57% of typical parents)
- Have a spouse or life partner** (9% compared to 51% of typical parents)
- Be valued by their community** (18% compared to 50% of typical parents)

**Participate in recreational activities** (20% compared to 50% of typical parents)

**Have strong religious affiliations** (19% compared to 36% of typical parents)

Kids with autism are also less likely than their typically developing peers to have bank accounts (37% vs. 55%) and use electronic products like cell phones (9% vs. 41%) or MP3 players (23% vs. 49%) – tools of mainstream society.

**"What are his odds of finding a spouse and living a good life as an adult? How can I help him deal with being rejected by girls he likes?"**





***"If he doesn't make enough money, how will he support himself after I'm gone?"***

**76% of teenagers with autism over the age of 16 have never looked for a job;** compared to only 23% of typical teenagers.

**76% of parents of children with autism are concerned about their child's future employment;** compared to only 35% of parents of typically developing children.

Only **29% of parents of children with autism believe their children will always have a place to live;** compared to 60% of parents of typically developing children.

**79% of children with autism are more likely to still be living at home beyond age 18;** compared to 32% of typically developing children.

***"My child is 24 years old and I am looking for quality health care – and for him to be able to find a job to take care of himself one day. That would be nice."***

Parents believe overall health will be an issue for their children with autism. In the

future, they will need more support than other children from health professionals, will have a harder time finding a physician who understands their needs, and will be less likely to have adequate health insurance.

Among parents of children with autism when asked about future health concerns, only:

**23% feel their children will have a primary care physician that understands their needs** (compared to 47% of typical parents)

**20% say their children will regularly exercise** (compared to 44% of typical parents)

**18% feel their children will have health insurance that adequately covers their needs** (compared to 42% of typical parents)

## A Snapshot of Family Life with Autism

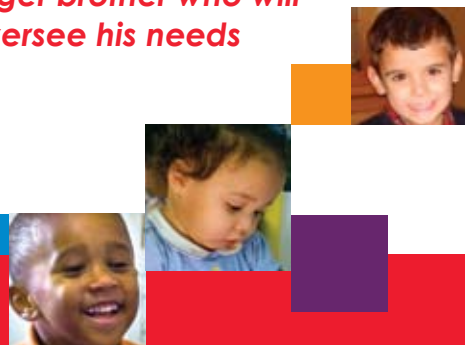
***"Help us find a way to help him. We can't do it ourselves."***

On the surface, families living with autism have a more family-friendly home than the typical American family does.

Somewhat counter to conventional wisdom about families living with a disability like autism:

**Families with autism are more likely to eat a sit-down dinner at home five days a week or more** (44% compared to 32% of typical parents).

***"I worry about his future, my future and the future of his younger brother who will be required to oversee his needs when I'm gone."***



Day-to-day routines for families living with autism are much more time consuming:

When **getting ready in the morning, it takes families of children with autism 55 minutes** compared to 46 minutes for typical families.

And in **preparing for bed at night, it takes 46 minutes for families of children with autism** compared to 35 minutes for typical families.

Parents of children with autism don't receive any more support from their extended family members than do typical parents.

***“How do I keep my sanity? How do I care for his typically developing siblings and preserve my marriage?”***

## **Financial Planning: Of Great Concern, Yet Done Little About**

***“We are drowning financially.”***

Parents of children with autism have much stronger financial concerns for their families than typical parents.

Topping the list – 74% of parents of children with autism fear their children will not have enough financial support after they die, while only 18% of typical parents share this fear.

They express extreme financial strains and costs associated with caring for a child with autism, with more than half stating that the cost of caring for my child:

**Drains my family's current financial resources** (52% compared to 13% of typical parents)

**Will drain my family's future finances** (50% compared to 10% of typical parents)

**Will cause me to fall short of cash during retirement** (54% compared to 13% of typical parents)

**Financially impacts raising typically developing siblings** (47%)

Parents of children with autism also are:

Almost four times more likely than typical parents to feel their children will not have financial independence, with only 12% feeling their children will be able to handle personal day-to-day finances.

Much more likely to incur debt to meet their families' many needs.

Unfortunately, many insurance companies do not cover treatment and services for people living with autism. And generally, families must cover the lifelong cost of care and treatment for their family member with autism. Often parents feel their children with autism who are higher-functioning or have Asperger's are overlooked for benefits. The reality is: these individuals do require support to be successful in life.

Yet, few have taken steps to ensure their children's financial future, with only:

- **50% looking to a professional for financial advice**
- **38% designating a guardian or creating a will**
- **17% establishing a special needs trust**
- **24% identifying living arrangements if the parent is no longer living**



# Education: Prepared for Life?

*“What happens after high school? We have fallen into a black hole. Everything stopped and now we are on our own.”*



When it comes to education, parents of children with autism are truly worried their children won't be prepared for life after school and age 21.

Only 19% of parents who have children with autism feel their children's education will adequately prepare them for life, compared to 56% of typical parents. They also have fairly low expectations for their children's education, as not even half (46%) expect their children with autism to receive education beyond a high school diploma. Whereas, nearly 80% of typical parents believe their children will receive some type of education beyond high school (associates, college and graduate degrees).

However, parents of children that have Asperger's are seemingly less concerned with their children's education than are

parents of children with other types of autism. They also have higher expectations – with 70% of children with Asperger's thought of as college-bound.

*“I want to know how to find the right education for my son. I know he could do so much better.”*

In the classroom, parents believe their children with autism are functioning at an education level lower than their peers:

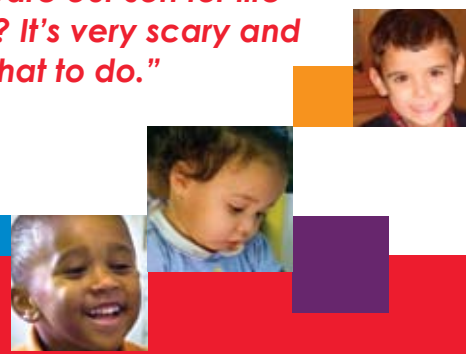
**2 out of 3 parents say their children with autism have slightly and much lower literacy and math skills than their peers.**

**However, according to their parents, children with Asperger's are more likely to not only function at an appropriate age level, but also have slightly and much higher literacy and math skills than their peers.**

*“What resources are available after our child ages out of the educational system? How will we best fill our child's life after he is finished with school? Are there adult support services when he no longer qualifies for school-related educational services at age 21?”*

Additionally, parents of children with autism are more likely to give a lower rating (48% compared to 26% of typical parents) to the quality of education their children have received. Parents often perceive that their children with autism are completing grade levels (perhaps being passed through) even though they are not functioning at these grade levels.

*“How do we prepare our son for life after high school? It's very scary and we don't know what to do.”*



## Methodology

This Easter Seals' Living with Autism Study was conducted online within the United States by Harris Interactive on behalf of Easter Seals between June 16 and July 17, 2008, among 1,652 parents of children age 30 and under who have autism and 917 parents of typically developing children age 30 and under. No estimates of theoretical sampling error can be calculated; a full methodology is available.

## 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).

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## 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; 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 is on the Internet at [www.massmutual.com](http://www.massmutual.com).

## About the Autism Society of America (ASA)

ASA, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. We do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy. For more information, visit [www.autism-society.org](http://www.autism-society.org).

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