

Easter Seals Living with Disabilities Study Key Findings



Only 11% of parents of adult children with disabilities report their child is employed full time (or 19% part time), while 48% of parents of adults without disabilities report the same (or 24% part time).



Through Parents' Eyes: Huge Disparities

Many of us take the basics of daily adult life for granted. We hold true to our beliefs about what constitutes the American dream -- even during an economic recession.

In most cases, we have a place to live – often, of our own choosing. We access transportation to get us to and from work or the grocery store or the movies. We manage our own money – money we earn from paid employment. We feel financially independent and see at least some security in our financial future. We're a part of our community, and we have friends and a life partner with whom we share similar interests. Our education generally helped prepare us for the adult world. We've got the basics covered.

When we consider our adult children, the same can most likely be said for their daily lives, too. This is what makes up the foundation upon which we, and our children, can build and go about our lives.

But what happens if you're one of the millions of adults living with a developmental disability in this country? Or the parent and caregiver to an adult child with a disability? How is your life different? Are the basics covered?

As a leading provider of services for people living with disabilities, Easter Seals knows how challenging life for an adult with a disability – and his/her family – can be. Everyday, we see the struggles and obstacles families face. We hear their fears for the future expressed in chilling terms: "What will happen to my son when I die? Who will care for him, see that he has a place to live and money to survive?"

After age 21, young adults with disabilities "age out" of the services and supports provided by law through the school system. Whatever help families living with disabilities may have received through childhood simply, and quite suddenly, goes away. In its stead,

families are often met with heightened concerns about their adult child's immediate needs for employment, housing, independence, transportation, social interactions, recreation, healthcare, and financial security.

Easter Seals Living with Disabilities Study*

Easter Seals Living with Disabilities Study, made possible by MassMutual Financial Group, and conducted online by Harris Interactive in August and September 2010, provides new insight into these challenges facing adults with developmental disabilities and parents of adult children with disabilities, as compared to parents of adult children without disabilities. In every measure of comparison, we found parents of adult children with disabilities had significantly higher levels of concern for their children than parents of adult children without disabilities. There is a consistent, notable gap between the two groups across every aspect of life.

A few examples:

- Only 11% of parents of adult children with disabilities report their child is **employed** full time (or 19% part time), while 48% of parents of adults without disabilities report the same (or 24% part time).
- Just 6 in 10 parents of adult children with a disability (61%) rate their child's **quality of life** as excellent or good, compared to 8 in 10 parents of adults without a disability (82%).
- Huge gaps exist in parents of adults with disabilities' assessment of their child's ability to manage their own **finances** (34% vs. 82% parents of adults without disabilities) and have the life skills necessary to **live independently** (30% vs. 83% parents of adults without disabilities).
- Almost 7 in 10 adults with disabilities (69%) **live with their parent(s)** or guardian, only 17% live independently – compared to more than half of adult children without disabilities (51%).

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

In this report we'll examine a few top line results from parents' perspective:

- After Age 21- Now What?
- Future Fears
- Highs and Lows
- Family Life: Together We're Stronger

We'll also report what we learned from adults living with disabilities in: Adults with Disabilities: Education and Independent Living.

A full version of the study is available at www.easterseals.com.

After Age 21 – Now What?

When asked to describe their adult son or daughter, parents largely agree their adult child (without a disability) regularly participates in recreational activities, has friends, has financial independence, manages their own finances, exercises regularly, has a paying job, can access transportation, has a place to live, is valued by community, and has received an education that's adequately prepared them for life.

Parents of adult children with disabilities have a vastly different response. Across the board, there are huge disparities among parents of adult children with disabilities as compared to their non-disabled counterparts.

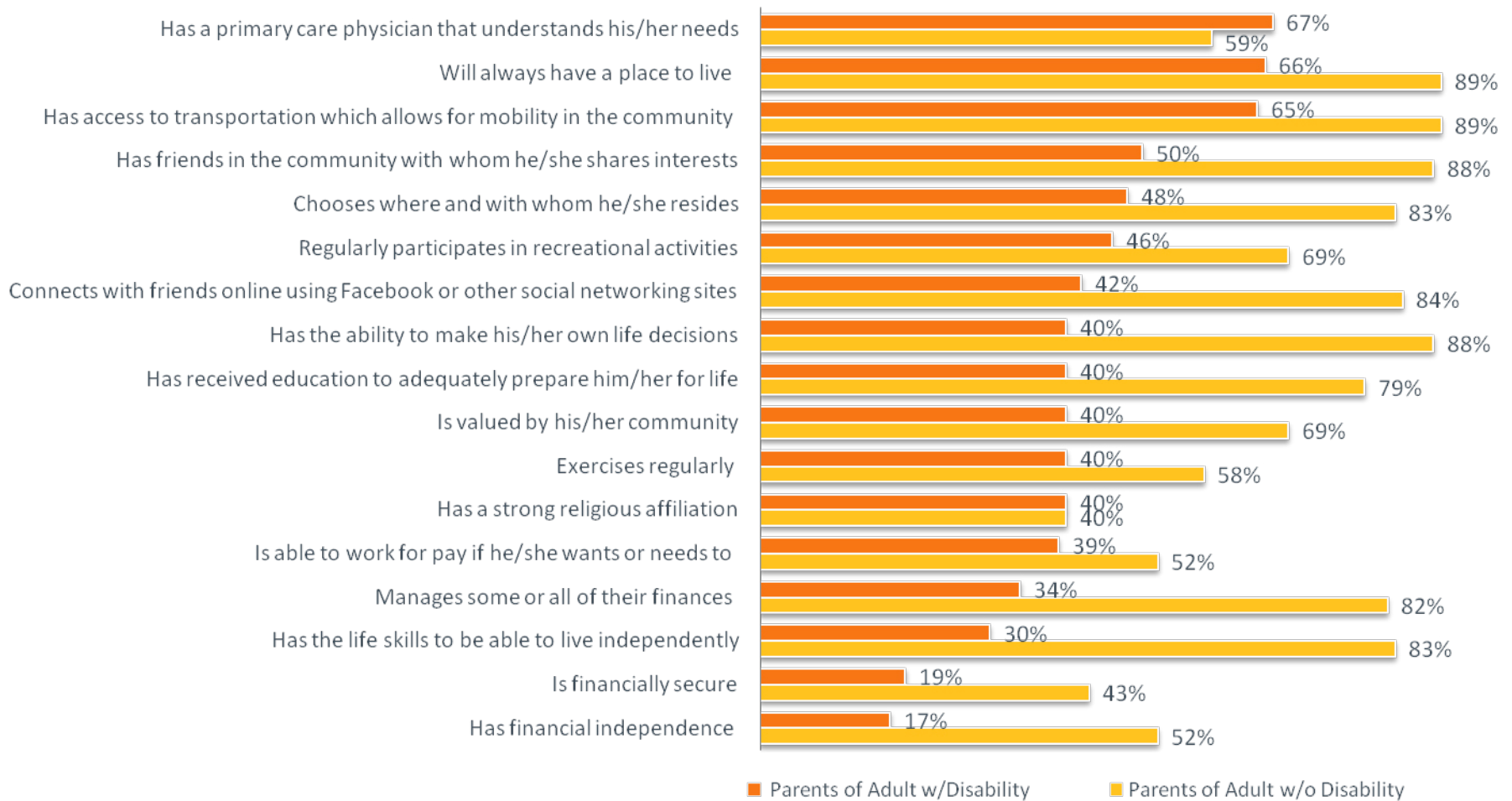
- 74% of parents strongly or somewhat disagree their adult child

with a disability as financially independent; while more than half (52%) of parents strongly or somewhat agree their adult children without disabilities are financially independent.

- Only 39% of parents strongly or somewhat agree their adult child with a disability is able to work for pay if he/she wants to, compared to nearly all (92%) of parents of adult children without a disability.
- Only 45% of parents strongly agree their adult child with a disability will always have a place to live; whereas, 75% of parents of adult children without a disability strongly agree.
- Only 40% of parents think their adult child with a disability received an education that adequately prepared him/her for life; parents of adult children without disabilities are far more pleased (79%) with their child's educational preparation.
- When considering overall life skills and ability to live independently, 62% of parents strongly or somewhat disagree their adult child with a disability can take care of themselves; conversely, 83% of more typical parents strongly or somewhat agree their adult child can.
- Similarly, 54% don't think their adult child with a disability has the ability to make his/her own life decisions; with 88% of more typical parents responding affirmatively, their adult child without a disability can make their own life decisions.

"My son's disability has affected every aspect of our lives. Now that he is a young adult, we realize that he will never be able to live alone independently, so all of our family's decisions (financial, emotional, career, residential) are influenced by that knowledge."

Parents are least likely to report their adult child with a disability is independent, especially when it comes to finances and the ability to live independently.



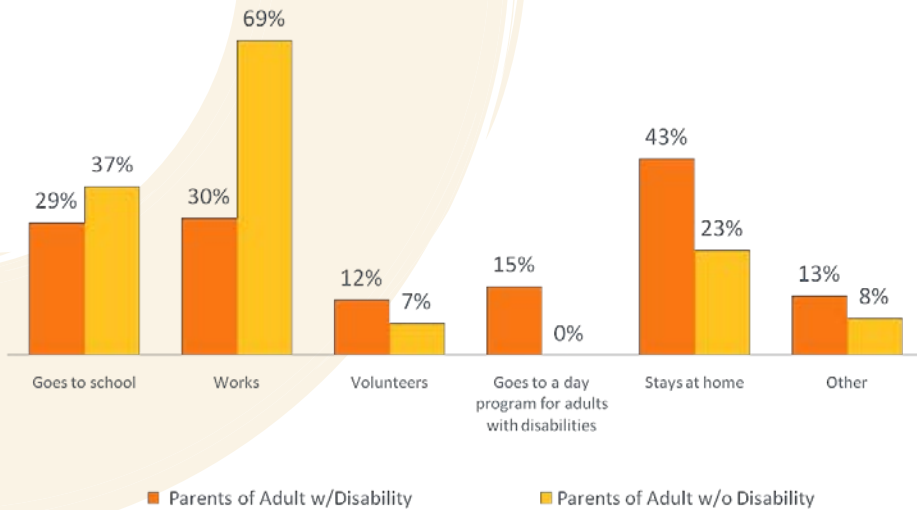
BASE: ALL QUALIFIED RESPONDENTS (Top 2 Box)

Q725 Please indicate whether each of the following describe your X-year old son/daughter?

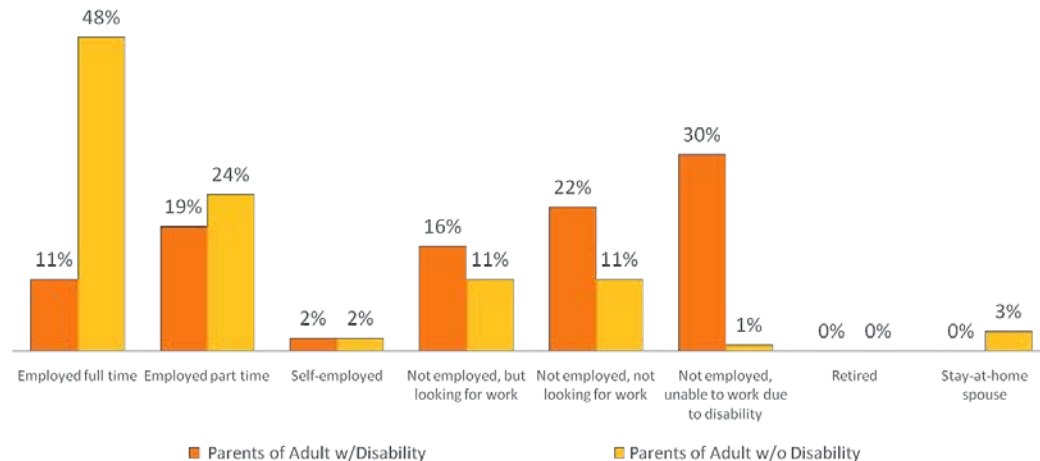
Only 40% of parents think their adult child with a disability received an education that adequately prepared him/her for life; parents of adult children without disabilities are far more pleased (79%) with their child's educational preparation.



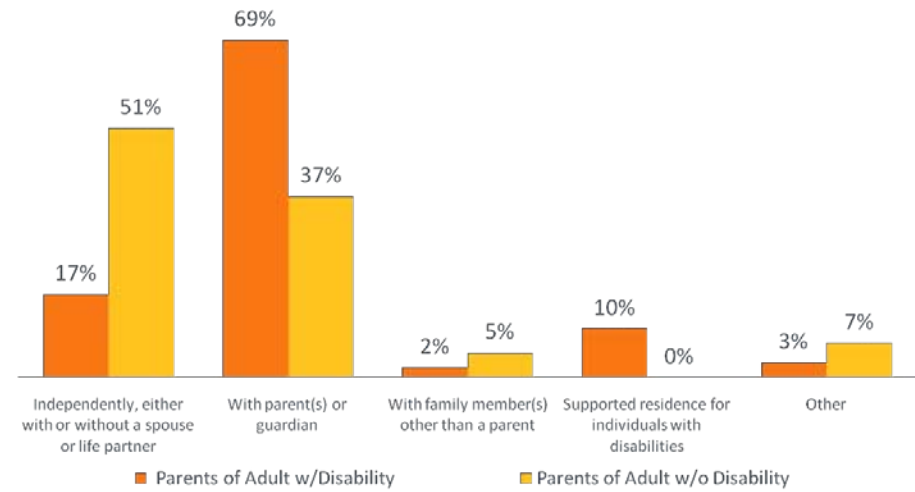
While some adult children with disabilities work (30%) or go to school (29%), nearly half (43%) stay at home each day.



There is a large difference in full-time employment between adult children with disabilities and those without. Parents report only 11% of adult children with disabilities are employed full time, compared to 48% of adult children without disabilities.



According to parents, nearly 7 in 10 adults with disabilities (69%) live with their parents or guardian – while more than half of adults without disabilities live independently.



Parents of adult children with disabilities feel their child's education did not prepare them:

- To live independently (45% compared to 12% of adults without disabilities)
- For gainful employment (38% compared to 9% of adults without disabilities)

Across the board, parents of adults with disabilities were less likely to say their child owns/uses the following items:

- Bank account (71% vs. 89%)
- Personal computer (67% vs. 87%)
- Cell phone (62% vs. 97%)
- Credit card (25% vs. 57%)
- MP3 player (50% vs. 71%)



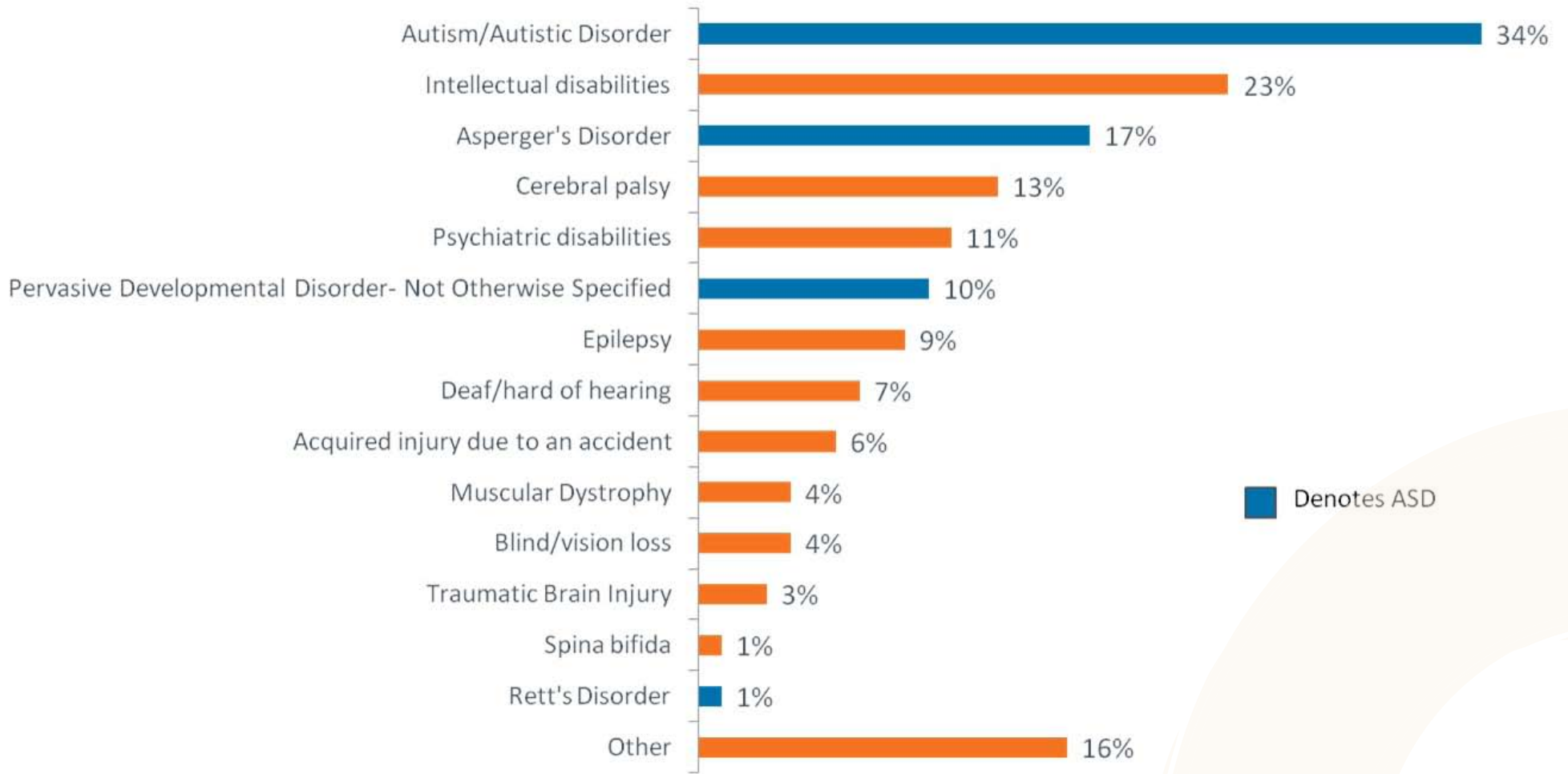
“It breaks my heart to see him try so hard to be independent. His inability to comprehend social nuances and relating to others keeps him so vulnerable and dependent on us. He wants to work full-time and have his own place, but it doesn’t seem like it will ever happen. I feel hopeless sometimes and afraid about what will happen to him when we’re gone.”

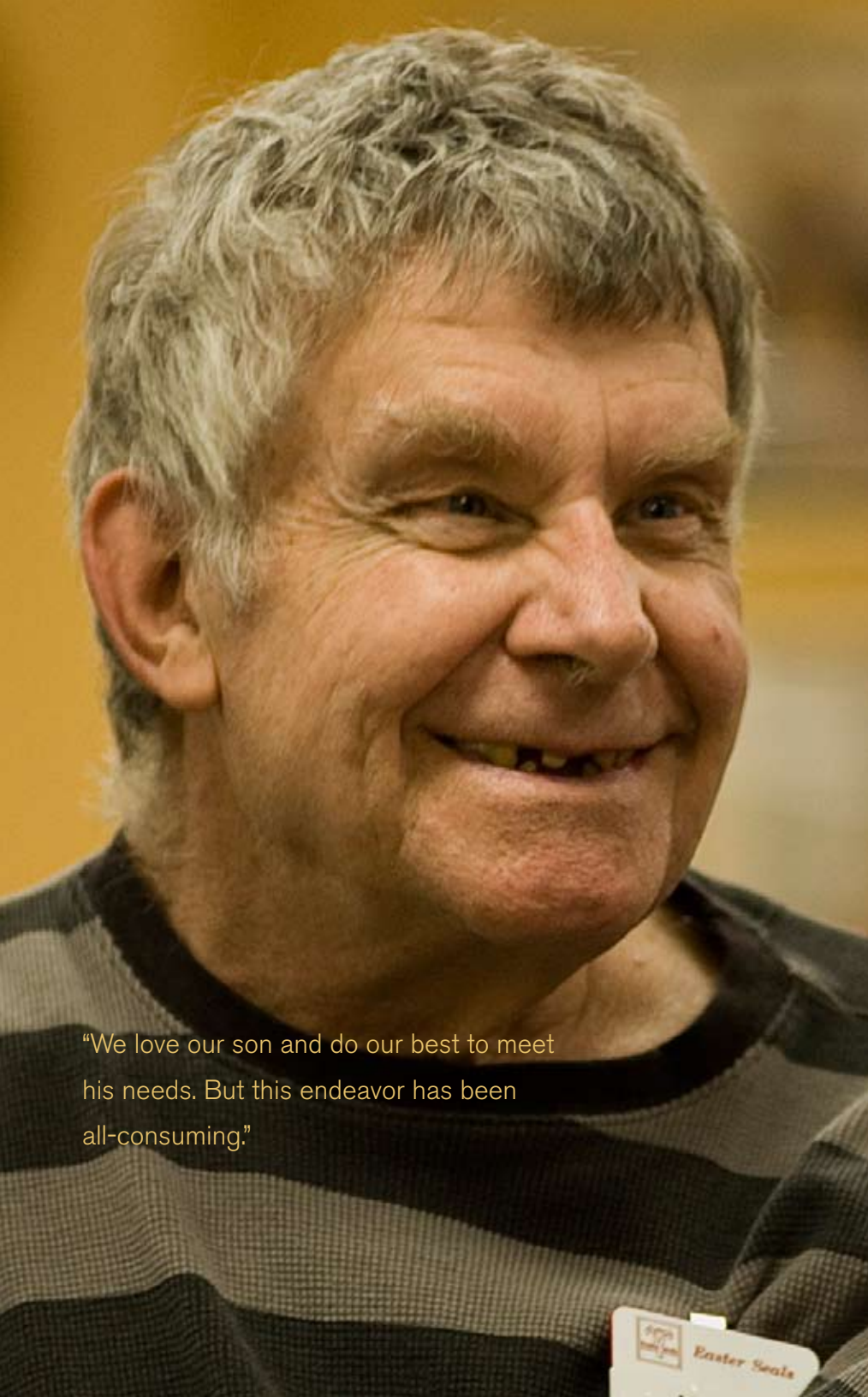
When it comes to building friendships and having fun, parents of adult children with disabilities are far less likely to say their child:

- Has friends in the community with whom he/she shares interests (50% vs. 88% of adults without disabilities)
- Regularly participates in recreational activities (46% vs. 69%)
- Connects with friends online via Facebook or other social networks (42% vs. 84%)
- Exercises regularly (40% vs. 58%)

“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.”

Parents report nearly two-thirds (62%) of the adult children with disabilities in the study have some form of autism.





“We love our son and do our best to meet his needs. But this endeavor has been all-consuming.”

Future Fears

A majority of parents of adult children with disabilities feel their son/daughter is unprepared for their future, whereas a strong majority of parents of adult children without disabilities feel their child is well prepared.

| Parents of Adults with Disabilities | Parents of Adults without Disabilities |
|-------------------------------------|--|
| Very or Somewhat Prepared 45% | Very or Somewhat Prepared 75% |
| Very or Somewhat Unprepared 55% | Very or Somewhat Prepared 25% |

In fact, parents of adults with disabilities have far greater levels of concern about their son or daughters' future across many areas of life, compared to parents of adults without disabilities. They are extremely or very concerned about:

- Financial well-being (52% vs. 22%)
- Quality of life (48% vs. 14%)
- Employment (47% vs. 17%)
- Housing needs (46% vs. 13%)
- Independence (45% vs. 14%)
- Build or have meaningful friendships (41% vs. 10%)
- Health (38% vs. 15%)
- Longevity of life (29% vs. 11%)
- Education (23% vs. 13%)

“She grieves over not driving, marrying, having children; I grieve with and for her.”

Parents of adult children with disabilities are very fearful of what will happen after they die -- they have multiple fears about what will happen to their adult child following their death. While parents of adult children without disabilities cite no fears for what will happen to their child after their death.

- His/her emotional stability (61% vs. 16%)
- His/her quality of life (61% vs. 14%)
- His/her living situation (55% vs 13%)
- His/her finances (52% vs. 23%)
- He/she will not receive the support he/she needs (55% vs. 8%)
- He/she will not be able to support himself/herself (50% vs. 11%)
- He/she will not be able to afford medical care (31% vs. 11%)
- I don't have any fears about my X-year-old son/daughter after I die (15% vs 60%)

Yet, given parents many fears and concerns for their adult children with disabilities, nearly one third (32%) have done little to nothing to prepare. Most commonly, parents have created a will (41%) and designated a guardian (30%).

Approximately 4 in 10 parents of adult children with disabilities (36%) report their other children are planning to take care of their sibling with a disability when they die. Another 31% don't know if their other children will step into that caregiver role.

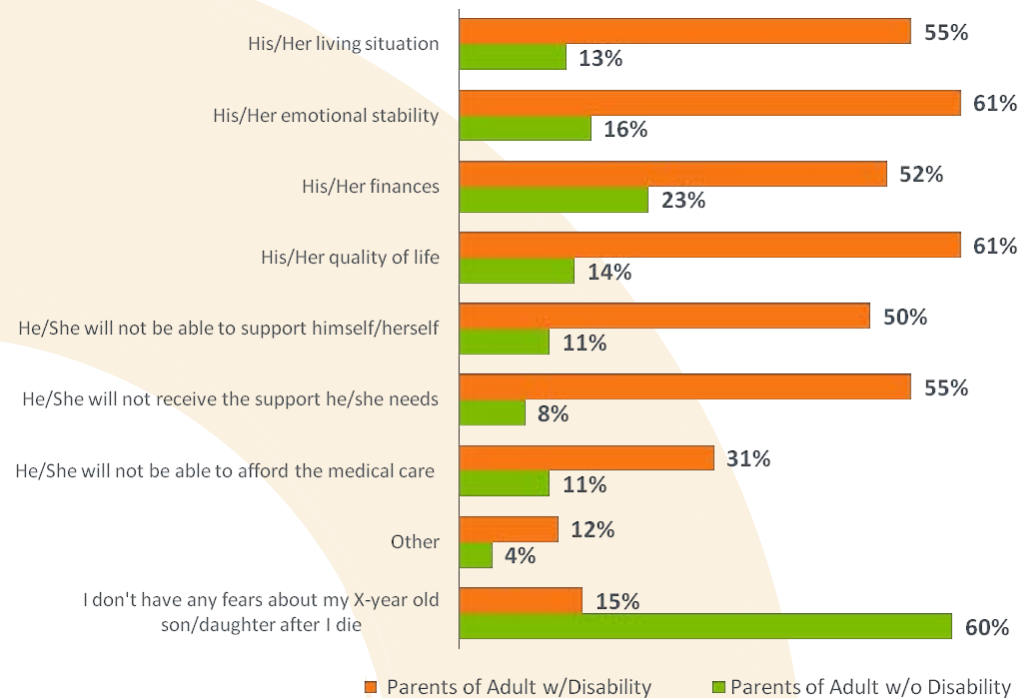
- Guardianship for an adult with a disability most commonly falls to another family member (37%), or his/her other parent (25%), or his/her sibling (20%) in the event the primary caregiver is no longer able to provide care.

Nearly two-thirds (62%) of parents state they do not have a life care plan for their adult child with a disability.

“My emotional anxiety and stress levels are always very high. I constantly worry about our son and what his future holds, and how he will fare.”

“We have to find somewhere for him to live. Most parents raise their children so they are eventually self-sufficient. We cannot leave him alone.”

What do Parents fear most?



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 effected:

- The cohesiveness of my family (42%)
- The relationship with my partner/ spouse (32%)



Highs and Lows

When asked if their life had been negatively or positively impacted by their child's disability, many parents told us they struggled with this question. They felt raising a child with a disability well into and throughout adulthood is really a balance of extreme positives and extreme negatives, and they offered up several anecdotes and stories from their experience. Their lives seem to have been both negatively and positively impacted.

While half of parents of adult children with disabilities (54%) 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%
 - Age of parents 55+: 58%

In an unaided question, parents offered up numerous benefits to raising and caring for a child with a disability through adulthood:

- Patience (20%)
- Respect, acceptance of others (18%)
- My son/daughter is a wonderful, loving person (17%)
- Made me aware, knowledgeable (14%)
- Appreciate life to the fullest (13%)
- Empathy, compassion (11%)
- Became an advocate for people with disabilities (11%)
- My son/daughter is a wonderful, loving person (17%)
- Met others with similar experiences (8%)
- Made us/me strong, a better person (8%)
- Our family bonded, became closer (5%)

Parents most commonly delay or cancel plans for travel (34%), relocation (12%), returning to school (11%) and socializing (10%) to provide care for their adult son/daughter with a disability.

Parents cite savings for emergencies (51%) or retirement (49%) and family vacations (50%) as the areas most negatively impacted by having an adult child with a disability.

Family Life: Together we're Stronger

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%)
- The relationship with my other children (30%)

Parents also report a very high percentage of family involvement when it comes to supporting the needs of their adult child with a disability with daily activities.

- Parent/guardian (82%)
- Another family member (56%)
- Paid assistant, care provider (33%)

Yet, only a quarter of parents of adult children with disabilities report receiving a great deal/a lot of emotional support (26%). Parents receive little to no physical (82%) or financial (90%) support from family or friends.

"I have met so many wonderful advocates and families that have become friends. My son has taught me many valuable lessons. He is also a stabilizing influence on our family, bringing us closer together."



“We have a front-row seat to the best of human nature, and my other children have benefitted greatly from it.”

Adults with Disabilities: Education & the Ability to Live Independently

One clearly, very important area we have yet to discuss in detail is the responses from the nearly 400 adults living with disabilities who participated in the study. For Easter Seals Living with Disabilities Study, we asked adults with disabilities to comment on their own lives, their own personal experiences around life with a disability.

And, we ended up receiving a really unique sample of responses from this group – in fact, so unique that it's difficult, if not impossible, to compare the results from our adults with a disability to our other two parent groups' responses. A few reasons why:

Age: the mean age of our respondents for the overall study is between 50.3 and 55.3 years old, meaning the two groups of parents and the adults with disabilities are all about the same age. Our groups of parents answered our questions thinking about their children (who are predominately younger than age 35, averaging between 25-27 years old), while the adults with disabilities answered thinking about themselves (who are predominantly age 45 and older). You'll want to keep the generational differences in mind when reviewing the results as the adults with a disability are generally about 25 years older than the adult children upon which the parents' answers are based.

Education: The educational achievements of the adults with disabilities who took this survey far exceed the general public's level of education – with 43% of respondents achieving advanced graduate degrees, and another 22% graduating from a 4-year-college. This is a highly educated group of individuals. When looking at the adult children with disabilities, only 1% have participated in some graduate work, 5% have a college degree and 28% have graduated from high school.

Disabilities: The types of disabilities reported by the adults with disabilities and the parents of adult children with disabilities also vary. Eighteen percent of the adults with disabilities report having some form of autism, compared to 62% of parents of adult children with disabilities. The three most commonly reported disabilities for each group are:

- Adults with Disabilities: an injury acquired due to an accident (19%), psychiatric disabilities (11%), and cerebral palsy (10%)
- Parents of Adult Children with Disabilities: autism (34%), intellectual disabilities (23%), and Asperger's (17%)

A few key highlights from the adults with disabilities' responses:

- 59% of adults with disabilities classify the quality of their life as excellent or good
- Strong majorities of adults with disabilities are independent in their life decisions, finances, and living situations, have transportation and mobility in the community, and feel adequately prepared for life
- Most adults with disabilities own/rent their own home and live independently (82%) and another 45% have a life partner/spouse
- The vast majority of adults with disabilities feel their education prepared them, either a little or a lot, for gainful employment (81%) and living independently (70%)
- A strong majority of adults (85%) with disabilities mostly or always attended mainstream classes when attending school

Of those surveyed, adults with disabilities are primarily concerned with their future financial well-being, health, and quality of life and less concerned with longevity, friendships, and education. And the fears most commonly cited, if any, by adults with disabilities regarding their parent or guardian dying are emotional stability (33%), quality of life (29%), receiving necessary support (27%), and living situation (27%).

Yet, given adults with disabilities education, independence, quality of life, and ability to access to transportation, only 47% of adults with

disabilities are employed, 42% are unemployed – statistics far from the overall average unemployment rate. Two-thirds of adults with disabilities (66%) feel their employment situation is a good fit with their capabilities, while 34% feel they are under-employed and capable of more.

About the Research*

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, survey 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.

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
- Down syndrome
- Osteogenesis imperfecta
- Asperger's Disorder

- Epilepsy
- Pervasive Developmental Disorder - Not Otherwise Specified
- Autism/Autistic Disorder
- Fetal alcohol effect or fetal alcohol syndrome
- Psychiatric disabilities
- Blind/vision loss
- Fragile X Syndrome
- Rett's Disorder
- Cerebral palsy
- Intellectual disabilities
- Spina bifida
- Childhood Disintegrative Disorder
- Muscular Dystrophy
- Traumatic Brain Injury
- Deaf/hard of hearing

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.

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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, Inc., member FINRA and SIPC; OppenheimerFunds, Inc.; and The MassMutual Trust Company, FSB. For more information, visit www.massmutual.com.

