Background and Objectives

Easter Seals commissioned Harris Interactive to conduct a survey among adults living with disabilities, parents of adult children with disabilities whose cognitive abilities might prevent them from completing the survey themselves, and parents of adult children without disabilities. The survey was made possible by MassMutual Financial Group.

The purpose of this study is to:

- Gather and compile data to quantify anecdotal information about the disparity of supports for adults with disabilities needed to fully participate in their communities
- Gain insight from adults living with disabilities and their families – and call attention to the challenges they face
- Help service providers better respond to the needs of adults with disabilities and their families through relevant services and supports
- Provide data to support the need for new private and public funding to enhance resources for adults with disabilities and their families in key areas including school to work transition; employment; residential, transportation and community support and financial planning
- Advance awareness of study findings around newsworthy data to heighten awareness of the needs of adults living with disabilities and their families
Methodology

• This survey was conducted online within the United States by Harris Interactive on behalf of Easter Seals from August 18-September 13, 2010.
• Total respondents: 1,714 U.S. adults age 18+.
  – Adults with Disabilities, 18+ and having a disability (N=390)
  – Parents of Adults with Disabilities, parents of children 18+ who have a disability (N=318)
  – Parents of Adults without Disabilities, parents of children 18+ who do not have a disability (N=1006).
• Respondents for this survey were selected from various sample sources:
  – Adults with disabilities
    • Sample was provided by Easter Seals, Autism Society of America, National Council on Independent Living, American Assoc. of People with Disabilities and Justice For All
  – Parents of adult children with disabilities
    • Sample for this group came from two sources:
      – The same organizations noted above
      – Harris Poll Panel – during the screening process for Parents of Adults without Disabilities those who responded that they, in fact, had an adult child with a disability were included in this group
  – Parents of adult children without disabilities
    • Sample for this segment was selected from the Harris Poll Online database of adults who have agreed to participate in survey research
Methodology

- Results for Harris Poll respondents who qualified for Parents of Adults with Disabilities and Adults without Disabilities quotas were weighted for age, sex, race/ethnicity, education, region and household income to be representative of US consumers who are parents of adults with/without disabilities. Propensity score weighting was also used to adjust for respondents’ propensity to be online.

- All sample surveys and polls, whether or not they use probability sampling, are subject to multiple sources of error which are most often not possible to quantify or estimate, including sampling error, coverage error, error associated with nonresponse, error associated with question wording and response options, and post-survey weighting and adjustments. Therefore, Harris Interactive avoids the words “margin of error” as they are misleading. All that can be calculated are different possible sampling errors with different probabilities for pure, unweighted, random samples with 100% response rates. These are only theoretical because no published polls come close to this ideal.
Methodology

- The disabilities we included in the survey are listed below, and the adult child or adult with a disability had to have developed the disability prior to turning age 22 to qualify:

<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquired injury due to an accident</td>
<td>Down syndrome</td>
</tr>
<tr>
<td>Asperger’s Disorder</td>
<td>Epilepsy</td>
</tr>
<tr>
<td>Autism/Autistic Disorder</td>
<td>Fetal alcohol effect or</td>
</tr>
<tr>
<td></td>
<td>fetal alcohol syndrome</td>
</tr>
<tr>
<td>Blind/vision loss</td>
<td>Fragile X Syndrome</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>Intellectual disabilities</td>
</tr>
<tr>
<td>Childhood Disintegrative Disorder</td>
<td>Muscular Dystrophy</td>
</tr>
<tr>
<td>Deaf/hard of hearing</td>
<td></td>
</tr>
<tr>
<td>Osteogenesis imperfecta</td>
<td>Pervasive Developmental Disorder-</td>
</tr>
<tr>
<td></td>
<td>Not Otherwise Specified</td>
</tr>
<tr>
<td></td>
<td>Psychiatric disabilities</td>
</tr>
<tr>
<td></td>
<td>Rett’s Disorder</td>
</tr>
<tr>
<td></td>
<td>Spina bifida</td>
</tr>
<tr>
<td></td>
<td>Traumatic Brain Injury</td>
</tr>
</tbody>
</table>

- In the report, we reference a subgroup based on the amount of support a child with a disability needs (taken from responses at Q730). The subgroups and sample sizes are below:
  - Independent: n=184
  - Needs some support: n=72*
  - Needs a lot of support: n=62*

* Small sample sizes, please interpret with caution.
## Demographic Profile – Adult Children

<table>
<thead>
<tr>
<th>Education</th>
<th>Parents of Adult w/Disability: CHILD</th>
<th>Parents of Adult w/o Disability: CHILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than first grade</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>Some elementary school</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Some middle school</td>
<td>3%</td>
<td>0%</td>
</tr>
<tr>
<td>Some high school</td>
<td>17%</td>
<td>6%</td>
</tr>
<tr>
<td>Certificate of completion</td>
<td>26%</td>
<td>1%</td>
</tr>
<tr>
<td>Has high school degree or equivalent</td>
<td>28%</td>
<td>26%</td>
</tr>
<tr>
<td>Some college, but no degree</td>
<td>11%</td>
<td>33%</td>
</tr>
<tr>
<td>Associate degree</td>
<td>6%</td>
<td>9%</td>
</tr>
<tr>
<td>College degree</td>
<td>5%</td>
<td>17%</td>
</tr>
<tr>
<td>At least some graduate school</td>
<td>1%</td>
<td>8%</td>
</tr>
<tr>
<td>My child did not attend school</td>
<td>2%</td>
<td>0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Parents of Adult w/Disability: CHILD</th>
<th>Parents of Adult w/o Disability: CHILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>65%</td>
<td>74%</td>
</tr>
<tr>
<td>25-34</td>
<td>25%</td>
<td>17%</td>
</tr>
<tr>
<td>35-44</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>45-54</td>
<td>2%</td>
<td>3%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th>Parents of Adult w/Disability: CHILD</th>
<th>Parents of Adult w/o Disability: CHILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full time</td>
<td>11%</td>
<td>48%</td>
</tr>
<tr>
<td>Employed part time</td>
<td>19%</td>
<td>24%</td>
</tr>
<tr>
<td>Self-Employed</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Not employed but looking for work</td>
<td>16%</td>
<td>11%</td>
</tr>
<tr>
<td>Not employed and not looking for work</td>
<td>22%</td>
<td>11%</td>
</tr>
<tr>
<td>Not employed, unable to work due to a disability or illness</td>
<td>30%</td>
<td>1%</td>
</tr>
<tr>
<td>Retired</td>
<td>-</td>
<td>*</td>
</tr>
<tr>
<td>Stay-at-home spouse or partner/wife/husband</td>
<td>*</td>
<td>3%</td>
</tr>
</tbody>
</table>
# Demographic Profile – Parents and Adults with Disabilities

<table>
<thead>
<tr>
<th>Gender</th>
<th>Adults w/Disability</th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>33%</td>
<td>36%</td>
<td>47%</td>
</tr>
<tr>
<td>Female</td>
<td>67%</td>
<td>64%</td>
<td>53%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Adults w/Disability</th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>3%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>25-34</td>
<td>13%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>35-44</td>
<td>12%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>45-54</td>
<td>31%</td>
<td>34%</td>
<td>46%</td>
</tr>
<tr>
<td>55-64</td>
<td>30%</td>
<td>37%</td>
<td>23%</td>
</tr>
<tr>
<td>65 and over</td>
<td>11%</td>
<td>21%</td>
<td>22%</td>
</tr>
<tr>
<td>Mean Age</td>
<td>54.4</td>
<td>50.3</td>
<td>56.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Adults w/Disability</th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full time</td>
<td>31%</td>
<td>49%</td>
<td>52%</td>
</tr>
<tr>
<td>Employed part time</td>
<td>27%</td>
<td>32%</td>
<td>29%</td>
</tr>
<tr>
<td>Self-employed</td>
<td>17%</td>
<td>19%</td>
<td>13%</td>
</tr>
<tr>
<td>Not employed, but</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>looking for work</td>
<td>10%</td>
<td>2%</td>
<td>7%</td>
</tr>
<tr>
<td>Not employed and</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>not looking for work</td>
<td>8%</td>
<td>18%</td>
<td>22%</td>
</tr>
<tr>
<td>Unable to work due</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to a disability</td>
<td>29%</td>
<td>7%</td>
<td>6%</td>
</tr>
<tr>
<td>Retired</td>
<td>16%</td>
<td>24%</td>
<td>26%</td>
</tr>
<tr>
<td>Student</td>
<td>13%</td>
<td>1%</td>
<td>3%</td>
</tr>
<tr>
<td>Stay at home spouse</td>
<td>7%</td>
<td>16%</td>
<td>13%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Racial Background</th>
<th>Adults w/Disability</th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>78%</td>
<td>75%</td>
<td>78%</td>
</tr>
<tr>
<td>Black/African</td>
<td>3%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>Asian</td>
<td>1%</td>
<td>-</td>
<td>1%</td>
</tr>
<tr>
<td>Native American</td>
<td>1%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>Mixed</td>
<td>4%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Hispanic</td>
<td>4%</td>
<td>8%</td>
<td>9%</td>
</tr>
<tr>
<td>Decline To Answer</td>
<td>8%</td>
<td>6%</td>
<td>3%</td>
</tr>
</tbody>
</table>
## Demographic Profile - Parents and Adults with Disabilities

<table>
<thead>
<tr>
<th>Income</th>
<th>Adults w/Disability</th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $15,000</td>
<td>20%</td>
<td>5%</td>
<td>5%</td>
</tr>
<tr>
<td>$15,000 to $24,999</td>
<td>11%</td>
<td>6%</td>
<td>6%</td>
</tr>
<tr>
<td>$25,000 to $34,999</td>
<td>9%</td>
<td>5%</td>
<td>9%</td>
</tr>
<tr>
<td>$35,000 to $49,999</td>
<td>9%</td>
<td>17%</td>
<td>11%</td>
</tr>
<tr>
<td>$50,000 to $74,999</td>
<td>15%</td>
<td>14%</td>
<td>17%</td>
</tr>
<tr>
<td>$75,000 to $99,999</td>
<td>8%</td>
<td>10%</td>
<td>13%</td>
</tr>
<tr>
<td>$100,000 to $124,999</td>
<td>3%</td>
<td>11%</td>
<td>12%</td>
</tr>
<tr>
<td>$125,000 to $149,999</td>
<td>3%</td>
<td>3%</td>
<td>5%</td>
</tr>
<tr>
<td>$150,000 to $199,999</td>
<td>3%</td>
<td>3%</td>
<td>4%</td>
</tr>
<tr>
<td>$200,000 to $249,999</td>
<td>1%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>$250,000 or more</td>
<td>2%</td>
<td>2%</td>
<td>2%</td>
</tr>
<tr>
<td>Decline to answer</td>
<td>17%</td>
<td>22%</td>
<td>14%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Region</th>
<th>Adults w/Disability</th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>24%</td>
<td>22%</td>
<td>24%</td>
</tr>
<tr>
<td>Midwest</td>
<td>22%</td>
<td>18%</td>
<td>22%</td>
</tr>
<tr>
<td>South</td>
<td>28%</td>
<td>38%</td>
<td>30%</td>
</tr>
<tr>
<td>West</td>
<td>25%</td>
<td>23%</td>
<td>23%</td>
</tr>
</tbody>
</table>
Section I: Parents of Adult Children with and without Disabilities
Nearly two-thirds (62%) of the adult children with a disability have some form of an Autism Spectrum Disorder (ASD)

Parents of Adult w/Disability

- Autism/Autistic Disorder: 34%
- Intellectual disabilities: 23%
- Asperger's Disorder: 17%
- Cerebral palsy: 13%
- Psychiatric disabilities: 11%
- Pervasive Developmental Disorder- Not Otherwise Specified: 10%
- Epilepsy: 9%
- Deaf/hard of hearing: 7%
- Acquired injury due to an accident: 6%
- Muscular Dystrophy: 4%
- Blind/vision loss: 4%
- Traumatic Brain Injury: 3%
- Spina bifida: 1%
- Rett's Disorder: 1%
- Other: 16%

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITY (Q99/1) (n=318)
Q640. What kind of disability does your X-year old son/daughter/do you have?
In every case that was asked, parents of adults with disabilities are less likely to say their child owns/has that item

<table>
<thead>
<tr>
<th>Item</th>
<th>Gap (%)</th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bank account</td>
<td>18%</td>
<td>71%</td>
<td>89%</td>
</tr>
<tr>
<td>Personal computer</td>
<td>20%</td>
<td>67%</td>
<td>87%</td>
</tr>
<tr>
<td>Cell phone</td>
<td>35%</td>
<td>62%</td>
<td>97%</td>
</tr>
<tr>
<td>Credit card</td>
<td>32%</td>
<td>25%</td>
<td>57%</td>
</tr>
<tr>
<td>MP3 player</td>
<td>21%</td>
<td>50%</td>
<td>71%</td>
</tr>
</tbody>
</table>

**BASE:** ALL QUALIFIED RESPONDENTS (Q99/1)

Q710  Which of the following items does your x-year old son/daughter/you have?
Parents of adults with disabilities rate their child’s quality of life lower than parents of adults without disabilities, but the majority still say it’s excellent or good

Older parents of adults with disabilities are less likely to rate their child’s quality of life excellent or good than younger parents:

- 35-44: 79%
- 45-54: 60%
- 55+: 58%

**BASE: ALL QUALIFIED RESPONDENTS**
Q715 How would you rate your son’s/daughter’s/your quality of life?
Parents are least likely to report their adult child with a disability is independent, financially or having the ability to live independently

**Strongly/Somewhat Agree**

- Has a primary care physician that understands his/her needs: 59%
- Will always have a place to live: 66%
- Has access to transportation which allows for mobility in the community: 65%
- Has friends in the community with whom he/she shares interests: 89%
- Chooses where and with whom he/she resides: 88%
- Regularly participates in recreational activities: 83%
- Connects with friends online using Facebook or other social networking sites: 69%
- Has the ability to make his/her own life decisions: 84%
- Has received education to adequately prepare him/her for life: 79%
- Is valued by his/her community: 69%
- Exercises regularly: 58%
- Has a strong religious affiliation: 40%
- Is able to work for pay if he/she wants or needs to: 40%
- Manages some or all of their finances: 52%
- Has the life skills to be able to live independently: 34%
- Is financially secure: 19%
- Has financial independence: 43%

**BASE: ALL QUALIFIED RESPONDENTS (Top 2 Box)**

Q725 Please indicate whether each of the following describe your X-year old son/daughter?
Parents of adults with disabilities report their children are far less likely to have a spouse/life partner or live at their own residence.

**BASE: ALL QUALIFIED RESPONDENTS**

Q726. Please indicate whether each of the following describe your x-year old son/daughter/you.

- Has health insurance that adequately covers his/her needs
- Has a spouse or life partner
- Owns or rents his/her own residence

- **Parents of Adult w/Disability**
- **Parents of Adult w/o Disability**
Parents report while more than half of adults with disabilities are able to complete daily activities, a significant portion do need some or a lot of support.

**BASE: ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES**

Q730. Which one of the following best describes your x-year old son/daughter/you?
Parents of adults with disabilities report a very high percentage of family involvement when it comes to supporting their son/daughter with daily activities.

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES
Q735. When your x-year old son/daughter is at home, who supports him/her with daily activities when he/she need help?
Finances and transportation are the 2 key areas where parents of adult children with disabilities report needing the most assistance.

MANAGE FINANCES

- A lot of support: 66%
- A little support: 19%
- No support at all: 16%

PREPARE HIS/HER OWN MEALS

- A lot of support: 39%
- A little support: 31%
- No support at all: 30%

TRANSPORTATION

- A lot of support: 61%
- A little support: 16%
- No support at all: 22%

SHOP ON HIS/HER OWN FOR CLOTHING AND OTHER ITEMS

- A lot of support: 43%
- A little support: 31%
- No support at all: 26%

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES

Q740 How much support if any does your son/daughter need to do each of the following?
Parents report that one-third of adults with disabilities need a lot of help in all four areas asked.

Number of items each respondent needs a lot of support with (Manage finances, prepare own meals, transportation, shop for themselves)

- Needs a lot of support with all four items: 33%
- Needs a lot of support with three items: 13%
- Needs a lot of support with two items: 18%
- Needs a lot of support with one item: 16%
- Does not need a lot of support with any: 20%

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES
Q740 How much support if any does your son/daughter need to do each of the following?
According to parents, nearly 7 in 10 adults with disabilities live with their parents or guardian – while more than half of adults without disabilities live independently.

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

BASE: ALL QUALIFIED RESPONDENTS
Q745. Where does your x-year old son/daughter currently live?
Most support from family or friends is emotional support, though only a quarter of families with adults with disabilities report receiving a great deal or a lot of support emotionally.
While many adults with disabilities work or go to school, 2 in 5 stay at home each day, compared to 1 in 5 adults without disabilities.
There is a large difference in full time employment between adult children with disabilities and those without disabilities.

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

**BASE: ALL QUALIFIED RESPONDENTS**
Q807. Which one of the following best describes your x-year old son/daughter’s employment status?
Two-thirds of parents whose adult child with a disability is employed feel the job is an appropriate match for his or her capabilities.

_BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES WHOSE CHILD IS EMPLOYED_

Q.808 What best describes your x-year old son/daughter’s employment situation?
Almost three-quarters of parents of adults with disabilities believe their son or daughter’s math and literacy level is much or slightly lower than other people his or her age.

**Literacy level**
- 28% Much higher
- 15% Slightly higher
- 9% The same
- 16% Slightly lower
- 47% Much lower

**Math level**
- 8% Much higher
- 10% Slightly higher
- 10% The same
- 10% Slightly lower
- 72% Much lower

---

**BASE:** ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES
Q.815 In your opinion, what is your x-year old son/daughter’s literacy and math level compared to other people his/her age?
More than half of adult children with disabilities received disability-specific early intervention services before age 5

79% of adult children with disabilities who need a lot of support received disability-specific early intervention services before age 5

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES
Q817. Did your x-year old son/daughter receive disability-specific early intervention services/special education before age 5?
Generally, parents whose children received disability-specific early intervention services found them helpful or very helpful.

65% of parents of adults with disabilities who need a lot of support found these services somewhat or not at all helpful—compared to 43% of all parents whose children received these services.

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES WHOSE CHILD RECEIVED EARLY INTERVENTION SERVICES

Q818. How helpful do you think the disability-specific early intervention services/special education were in promoting your child’s overall development?
Nearly half of adult children with disabilities always or mostly attended special education classes

87% of adult children with disabilities who need a lot of support

BASE: CHILD ATTENDED SCHOOL
Q820. Did/does your x-year old son/daughter attend mainstream classes or special education classes?
Parents of adults with disabilities report that generally the education their children received did not prepare them well.
While half of parents of adults with a disability report being negatively impacted by their child’s disability, 30% say their quality of life has been positively impacted.
51% of parents report their child’s disability having a negative affect on their family

The more support the child needs, the more negative the affect on the family:

- Independent: 47% somewhat/very negative
- Needs some support: 56% somewhat/very negative
- Needs a lot of support: 62% somewhat/very negative

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES
Q915 In general, how has your x-year old son/daughter’s developmental disability affected your family?
The cohesiveness of the family is one area that has been the most positively impacted by having a child with a disability

### % very/somewhat positively

- **The cohesiveness of my family**: 42%
- **The relationship with my spouse or partner**: 32%
- **The relationship with my other children**: 30%
- **My interactions with my friends and acquaintances**: 26%
- **My interactions with my extended family**: 24%

**BASE:** ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (TOP 2 Box)

Q945 How positively or negatively do you think having a child with a disability has impacted each of the following?
The majority of parents of adult children with disabilities give more attention to their son/daughter with a disability compared to their other children without disabilities.
Parents who spent more time with their child with a disability than their other children reported ‘not enough time spent with the other children,’ ‘feelings of jealousy in the other child/ren’ and the other children ‘feeling cheated’

- Disabled child needs are greater/not enough time spent with other children: 25%
- My other child/children was/were more independent and understanding: 25%
- There was and is some resentment/jealousy: 22%
- They felt/feel cheated: 22%
- Not much, as other children are/were older: 7%
- It was a problem when they were younger: 5%
- Other: 17%
- None: 7%
- Don't know: 2%

BASE: SPENDS MORE TIME WITH CHILD WITH DISABILITY
Q927: How do you think the amount of time you spend with your x-year old son/daughter impacted your other children?
The majority of parents who have other children do not rely on them to meet the needs of their adult child with a disability.
A majority of parents of adults with disabilities have talked with their other children about who will take care of their child with a disability in the event of their death.

More than ¾ of parents 35-44 have talked to their other children about who will take care of their child with a disability when they die (77%)

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES WITH OTHER CHILDREN (n=250)
Q935. Have you spoken to your other children about who will take care of your x-year old son/daughter after you die?
About 4 in 10 parents of adults with disabilities report their other children are planning on taking care of their sibling with a disability when their parents die.

Almost a third of parents do not know if their other children will take care of their child with a disability after their death.

**BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES WITH OTHER CHILDREN**

Q940. Do your other children plan to take care of your x-year old son/daughter after you die?
A majority of parents have delayed or opted not to do something in their life because they provide care for their adult son/daughter with a disability

**BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES**
Q.950.Is there anything in your life that you have put off or have decided not to do because you needed to take care of your x-year old son/daughter?
Parents most commonly delay or cancel plans for travel, relocation, returning to school, and socializing in order to provide care for their adult son/daughter with a disability.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travel/vacations/trips</td>
<td>34%</td>
</tr>
<tr>
<td>Moving to another location</td>
<td>12%</td>
</tr>
<tr>
<td>Going back to school</td>
<td>11%</td>
</tr>
<tr>
<td>Having a social life outside of the...</td>
<td>10%</td>
</tr>
<tr>
<td>Continuing my career</td>
<td>7%</td>
</tr>
<tr>
<td>Retirement</td>
<td>7%</td>
</tr>
<tr>
<td>Changing jobs</td>
<td>5%</td>
</tr>
<tr>
<td>Cannot work outside of the home</td>
<td>4%</td>
</tr>
<tr>
<td>Being in another committed...</td>
<td>4%</td>
</tr>
<tr>
<td>Recreational activities/hobbies</td>
<td>4%</td>
</tr>
<tr>
<td>Change in hours worked</td>
<td>3%</td>
</tr>
<tr>
<td>Other job/work mentions</td>
<td>3%</td>
</tr>
<tr>
<td>Getting married</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>8%</td>
</tr>
<tr>
<td>None/Nothing</td>
<td>27%</td>
</tr>
<tr>
<td>Decline to answer</td>
<td>5%</td>
</tr>
</tbody>
</table>

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES
Q955. What did you put off or decide not to do because you needed to take care of your x-year old son/daughter?
Unaided parents cite numerous benefits to caring for their adult son/daughter with a disability

- 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 very 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: 4%
- Don't know: 3%

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES
Q960. And in what ways do you think you have benefitted or that your life has been positively impacted from your experiences taking care of your x-year old son/daughter?
A majority of parents of adults with disabilities feel their son/daughter is unprepared for his/her future, whereas a strong majority of parents of adults without disabilities feel their child is prepared.

**Parents of Adult w/ Disability**

- **Prepared**: 45%
- **Unprepared**: 55%

**Parents of Adult w/o Disability**

- **Prepared**: 75%
- **Unprepared**: 25%

**BASE: ALL QUALIFIED RESPONDENTS**

Q1005. How well prepared do you feel your x-year old son/daughter is for his/her future /you are for your future?
Parents of adults without a disability are more confident in the job they did to prepare for their son/daughter’s future than are parents of adults with a disability

• **62%** of Parents of Adults without a Disability are Extremely/Very Confident in the job they did

• Only **27%** of Parents of Adults with a Disability are Extremely/Very Confident in the job they did

<table>
<thead>
<tr>
<th></th>
<th>Parents of Adult w/Disability</th>
<th>Parents of Adult w/o Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely confident</td>
<td>12%</td>
<td>29%</td>
</tr>
<tr>
<td>Very confident</td>
<td>15%</td>
<td>33%</td>
</tr>
<tr>
<td>Confident</td>
<td>25%</td>
<td>32%</td>
</tr>
<tr>
<td>Somewhat confident</td>
<td>18%</td>
<td>16%</td>
</tr>
<tr>
<td>Not at all confident</td>
<td>16%</td>
<td>4%</td>
</tr>
</tbody>
</table>

*BASE: ALL QUALIFIED PARENTS OF DISABLED AND NON DISABLED CHILDREN*  
Q1010. How confident do you feel about the job you did to prepare for your x-year old son/daughter’s future?
Parents of adults with disabilities have greater levels of concern about their son/daughters’ future, across different areas of life, than parents of adults without disabilities.

**BASE: ALL QUALIFIED RESPONDENTS (Top 2 Box)**

Q906. How concerned are you for x-year old son/daughter’s/your future in regard to each of the following areas?

<table>
<thead>
<tr>
<th>Area</th>
<th>Percentage Concerned</th>
<th>Gap</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial well-being</td>
<td>22%</td>
<td>30%</td>
</tr>
<tr>
<td>Health</td>
<td>15%</td>
<td>23%</td>
</tr>
<tr>
<td>Quality of life</td>
<td>14%</td>
<td>34%</td>
</tr>
<tr>
<td>Independence</td>
<td>14%</td>
<td>31%</td>
</tr>
<tr>
<td>Employment</td>
<td>17%</td>
<td>30%</td>
</tr>
<tr>
<td>Housing needs</td>
<td>13%</td>
<td>33%</td>
</tr>
<tr>
<td>Longevity of life</td>
<td>11%</td>
<td>18%</td>
</tr>
<tr>
<td>Build or have meaningful friendships</td>
<td>10%</td>
<td>31%</td>
</tr>
<tr>
<td>Education</td>
<td>13%</td>
<td>10%</td>
</tr>
</tbody>
</table>
A majority of parents of adults with disabilities have *multiple fears* for their son/daughter after their death, whereas a strong majority of parents of adults without disabilities cite *no fears* for their son/daughter after their death.

**Gap**

- 42%
- 45%
- 29%
- 47%
- 39%
- 47%
- 20%
- 8%
- 45%
The most common actions taken by parents of adults with disabilities to prepare for their son/daughter’s future are creating a will and designating a guardian; though nearly a third have taken none of the listed actions.

<table>
<thead>
<tr>
<th>Action</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Created a will</td>
<td>41%</td>
</tr>
<tr>
<td>Designated a guardian</td>
<td>30%</td>
</tr>
<tr>
<td>Created a special needs trust</td>
<td>27%</td>
</tr>
<tr>
<td>Will rely on siblings to care for the child</td>
<td>27%</td>
</tr>
<tr>
<td>Developed an estate plan</td>
<td>26%</td>
</tr>
<tr>
<td>Identified living arrangements if they are no</td>
<td>19%</td>
</tr>
<tr>
<td>longer living</td>
<td></td>
</tr>
<tr>
<td>Set up a savings account for the child</td>
<td>18%</td>
</tr>
<tr>
<td>Written a letter of intent</td>
<td>10%</td>
</tr>
<tr>
<td>Created a life care plan</td>
<td>6%</td>
</tr>
<tr>
<td>None of the above</td>
<td>32%</td>
</tr>
</tbody>
</table>

**BASE:** ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES

Q1030. In which of the following ways have you prepared for your x-year old son/daughter’s future when you die? Please select all that apply.
A majority of both groups of parents have created a will that includes their adult son/daughter, though a large number of each group have not.
Of adult children with disabilities who have a guardian (41% do not) that guardian is most likely their parent

- I am: 47%
- My child does not have a guardian: 41%
- His/Her other parent: 5%
- Another family member: 3%
- Other: 3%
- His/Her sibling: 1%
- A friend: 0%
- A lawyer: 0%

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES
Q1035. Who is currently your/you x-year old son/daughter’s guardian?
Guardianship for an adult with a disability most commonly falls to another family member in the event that the primary caregiver parent is no longer able to provide care.

- Another family member: 37%
- His/Her other parent: 25%
- His/Her sibling: 20%
- I will: 6%
- A friend: 3%
- A lawyer: 1%
- Other: 2%
- My child does not have a guardian: 7%

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES WHERE PARENT OR OTHER PARENT IS GUARDIAN

Q1040. Who will take over guardianship for your x-year old son/daughter if something happens to you/their other parent and you/the other parent is no longer able to fulfill that role?
Savings (emergencies or retirement) and family vacations were cited as the areas most negatively impacted by having an adult child with a disability.
Most parents of adults with disabilities have not incurred debt to meet family needs

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES
Q1105. Have you had to incur debt to meet family needs, due to your x-year old son/daughter?
More than half of parents of adults with disabilities do not utilize services specializing 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.
A strong majority of parents of adults with disabilities state their son/daughter receives government benefits

**BASE:** ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES

Q1150. Does your x-year old son/daughter/Do you receive government benefits?
According to parents of adults with disabilities, their son/daughter most commonly receives Supplemental Security Income (SSI)

- **Supplemental Security Income**: 60%
- **Medicaid**: 55%
- **Social Security Disability Income**: 44%
- **Medicaid waiver programs**: 23%
- **Vocational Rehabilitation Services**: 13%
- **Other**: 8%

**Base:** All qualified adults with disabilities and parents of adults with disabilities whose child receives government benefits

Q1155. Which of the following government benefits does your x-year old son/daughter? Please select all that apply.
The health insurance of more than 40% of parents of adults with disabilities either often or always pays for the services they require, while for a quarter of them, their health insurance never pays.

**BASE: ALL QUALIFIED RESPONDENTS**
Q1160. How often does your health insurance company pay, at least in part, for the services that you/your x-year old son/daughter requires?
Parents of adults with disabilities find information from other families in a similar situation and search engines to be most useful

Summary of Extremely/Very Useful

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (Top 2 Box)
Q1165. How useful do you find the following sources of information for supporting your x-year old son/daughter’s/your disability?
Nearly two-thirds of parents of adults with disabilities state they do not have a life care plan for their son/daughter.
Among those with a life care plan, their strategy most commonly addresses financial issues, medical care, type of supervision, residential needs, and social activities.

**BASE:** ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES AND HAS A LIFE CARE PLAN

Q1190  What does your life care plan/strategy for your x-year old son/daughter include? Please select all that apply.
Current resources most commonly utilized by parents of adults with disabilities are wills, government benefits, and life insurance policies.

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES
Q1197. Which of the following resources do you currently have in place for your children? Please select all that apply.
Section II: Adults with Disabilities
While many adults classify their disability as “other,” common disabilities are injuries due to accidents, psychiatric disabilities, cerebral palsy, and deafness/hardness of hearing.

BASE: ALL QUALIFIED RESPONDENTS (Q99/1) (n=390)
Q640. What kind of disability does your X-year old son/daughter/do you have?
Nearly all adults with disabilities surveyed possess a bank account and a computer; strong majorities have a cell phone and a credit card.

- Bank account: 96%
- Personal computer: 94%
- Cell phone: 86%
- Credit card: 75%
- MP3 player: 44%

**BASE: ALL QUALIFIED RESPONDENTS (Q99/1) (n=390)**

Q711 Which of the following items does your x-year old son/daughter/you have?
A majority of adults with disabilities classify their quality of life as either “Excellent” or “Good”

59% of adults with disabilities rate their quality of life as Good or Excellent

18% Excellent, 41% Good, 28% Fair, 11% Poor, 3% Terrible

Only 14% of adults with disabilities rate their quality of life poorly

BASE: ALL QUALIFIED RESPONDENTS (n=390)
Q715 How would you rate your son’s/daughter’s/your quality of life?
Strong majorities of adults with disabilities are independent in life decisions, finances, and living situations, have transportation and mobility in the community, and feel adequately prepared for life.
Most adults with disabilities who participated in the survey live on their own

- 68% have health insurance that adequately covers their needs
- 45% have a spouse or life partner
- 82% own or rent their own residence

**BASE:** ALL QUALIFIED RESPONDENTS (n=390)
Q726. Please indicate whether each of the following describe you
The majority of adults with disabilities report they are able to independently complete daily activities.
The majority of adults with disabilities surveyed receive assistance from a paid assistant or spouse/life partner when they need help with daily activities.

**BASE:** ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (n=138)

Q735. When you are at your home, who supports you with daily activities when you need help?
A majority of adults with disabilities require little to no support at all in each of the areas asked.

**MANAGE FINANCES**
- A lot of support: 14%
- A little support: 25%
- No support at all: 61%

**PREPARE HIS/HER/MY OWN MEALS**
- A lot of support: 22%
- A little support: 25%
- No support at all: 53%

**TRANSPORTATION**
- A lot of support: 27%
- A little support: 27%
- No support at all: 45%

**SHOP ON HIS/HER/MY OWN FOR CLOTHING AND OTHER ITEMS**
- A lot of support: 16%
- A little support: 28%
- No support at all: 56%

*BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (n=390)*

Q740 How much support if any do you need to do each of the following?
Most adults with disabilities – 7 in 10 – live independently

BASE: ALL QUALIFIED RESPONDENTS (n=390)
Q745. Where does your x-year old son/daughter/do you currently live?
Adults with disabilities participate in a wide range of activities during the work week

BASE: ALL QUALIFIED RESPONDENTS (n=390)
Q805. What do you do during a typical work week?
Nearly 6 in 10 (59%) adults with disabilities are either currently employed or seeking employment.

Employed: 47%
Un-employed: 42%
Retired: 12%
Most adults with disabilities feel their employment situation is a good fit with their capabilities

BASE: ALL QUALIFIED PARENTS OF ADULTS WITH DISABILITIES WHOSE CHILD IS EMPLOYED (n=182)
Q.809. What best describes your employment situation?
Adults with disabilities’ self-reported literacy and math levels are most often the same as or higher than those of other people their age, but they report much/slightly higher literacy levels more frequently than they do math levels.
Less than a quarter of adults with disabilities received disability-specific early intervention services before age 5

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (n=390)
Q817. Did your x-year old son/daughter/you receive disability-specific early intervention services/special education before age 5?
Of those who received disability-specific early intervention, 9 in 10 adults with disabilities state the services they received were at least somewhat helpful in promoting their development.
Of those who responded to this survey, more than 70% of adults with disabilities have attained an associate degree or higher, and less than 10% did not finish high school.
The vast majority of adults with disabilities feel their education prepared them, either a little or a lot, for gainful employment and living independently.

**BASE: ALL QUALIFIED RESPONDENTS (n=390)**
Q.830. How much did the education you received prepare you/him/her for each of the following?
Many adults with disabilities (48%) state their disability has affected their family negatively.

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES  (n=708)
Q815 In general, how has your X-year old son/daughter’s/your developmental disability affected your family?
A strong majority of adults (85%) with disabilities mostly or always attended mainstream classes when attending school.
Nearly 7 in 10 adults with disabilities (68%) report the quality of their lives has been negatively impacted by their disability.

**BASE:** ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (n=390)
Q905. How has your quality of life been impacted by your x-year old son/daughter’s/your disability?
For each attribute, adults with disabilities generally feel their disability has had more of a negative impact

For each attribute, adults with disabilities generally feel their disability has had more of a negative impact.
The majority of adults with a disability feel prepared for their future

<table>
<thead>
<tr>
<th>Prepared</th>
<th>61%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unprepared</td>
<td>39%</td>
</tr>
</tbody>
</table>

**BASE: ALL QUALIFIED RESPONDENTS (n=390)**
Q1005. How well prepared do you feel your x-year old son/daughter is for his/her future /you are for your future?
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.

BASE: ALL QUALIFIED RESPONDENTS (Top 2 Box) (n=390)
Q806. How concerned are you for x-year old son/daughter’s/your future in regard to each of the following areas?
Fears most commonly cited, if any, by adults with disabilities regarding their parent or guardian dying are emotional stability, quality of life, receiving necessary support, and living situation.

- My emotional stability: 33%
- My quality of life: 29%
- My living situation: 27%
- I will not receive the support I need: 27%
- My finances: 26%
- I will not be able to support myself: 22%
- I will not be able to afford the medical care: 16%
- Other: 15%
- I don't have any fears about my parent or guardian dying: 42%
While a strong majority of adults with disabilities state their parents have taken none of the listed actions to prepare for their future after their parents’ death, more than a quarter state their parents have created a will.
A majority of adults with disabilities do not have a guardian or are their own guardian

- I am: 49%
- My parents: 38%
- Another family member: 8%
- A friend: 1%
- My siblings: 1%
- A lawyer: 1%
- I do not have a guardian: 2%

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (n=390)
Q1035. Who is currently your/your x-year old son/daughter’s guardian?
Adults with disabilities recognize their parents or guardians have made sacrifices to accommodate their needs

- Time spent doing other things: 40%
- Family vacations: 26%
- Saving for retirement: 22%
- Eating at restaurants: 17%
- Extracurricular activities for their other children: 12%
- Saving for college education for their other children: 9%
- Buying a house: 8%
- Other: 4%

BASE: ALL QUALIFIED RESPONDENTS WITH A DISABILITY (n=390)
Q115. Which of the following, if any, have your parents or guardian sacrificed in order to accommodate the financial demands of your disability on your family?
More than half of adults with disabilities do not utilize services specializing in assisting with issues related to their disability.

Q1140. Do you utilize services that specialize in helping you deal with life issues related to your x-year old son/daughter’s/your disability?
Among those adults with disabilities who utilize specialty services, the majority receive advice on health issues.

- **Health**: 55%
- **Emotions**: 33%
- **Stress management**: 27%
- **Diet**: 25%
- **Employment**: 25%
- **Interventions/Treatments**: 24%
- **Finances**: 23%
- **Spirituality**: 22%
- **Tax planning or estate planning**: 20%
- **Shelter**: 13%
- **Family life**: 11%
- **Retirement**: 10%
- **End-of-life issues**: 8%
- **Entertainment**: 7%
- **Sexuality**: 7%
- **Life insurance**: 7%
- **Clothing**: 5%
- **Other**: 14%
- **Not sure**: 13%

**BASE**: UTILIZES SPECIALIZE SERVICES HELPS IN DEALING LIFE ISSUES (n=166)

Q1145. In which of the following areas of your life do you receive advice from anyone who specializes in helping you deal with life issues related to having a child with disabilities/your disability?
More than half of adults with disabilities receive government benefits

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES (n=390)
Q1150. Does your x-year old son/daughter/Do you receive government benefits?
According to adults with disabilities, Social Security Disability Income (SSDI) is the most common type of benefits they receive.

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Security Disability Income</td>
<td>64%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>34%</td>
</tr>
<tr>
<td>Supplemental Security Income</td>
<td>27%</td>
</tr>
<tr>
<td>Vocational Rehabilitation Services</td>
<td>18%</td>
</tr>
<tr>
<td>Medicaid waiver programs</td>
<td>15%</td>
</tr>
<tr>
<td>Other</td>
<td>28%</td>
</tr>
</tbody>
</table>

BASE: ALL QUALIFIED ADULTS WITH DISABILITIES AND PARENTS OF ADULTS WITH DISABILITIES WHOSE CHILD RECEIVES GOVERNMENT BENEFITS (n=204)

Q1155. Which of the following government benefits does your x-year old son/daughter/do you receive? Please select all that apply.
The health insurance of nearly 60% of adults with disabilities either often or always pays for the services that they require.

BASE: ALL QUALIFIED RESPONDENTS  (n=390)
Q1160. How often does your health insurance company pay, at least in part, for the services that you/your x-year old son/daughter requires?
Very few adults with disabilities required assistance from another party while responding to the questions in this survey.

**BASE: ALL QUALIFIED ADULTS WITH DISABILITIES (n=390)**

Q1176. Throughout the survey, did you have any help from another individual while answering any of the questions?
Of the 8% who received assistance with the survey, more than half say they received a significant amount of help.

- A minimal amount of help: 20%
- A moderate amount of help: 27%
- A significant amount of help: 53%

**BASE: YES, RECEIVED HELP** (n=30)

Q1177. Would you say the help you received taking this survey was...?
For more information and local services and support, visit
[www.easterseals.com](http://www.easterseals.com)