



# RESEARCH BRIEF

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## Sibling Caregiver Outcomes: Results from the Arc's 2010 FINDS Survey

**Lynda Lahti Anderson, MA, MPH, RTC Institute on Community Integration, University of Minnesota**

**John Reagan, BA, RTC Institute on Community Integration, University of Minnesota**

**Amy Hewitt, PhD, RTC, Institute on Community Integration, University of Minnesota**

**Amie Lulinski, PhD, The Arc**

**Catherine Keiling Arnold, MA, Institute on Disability and Human Development, University of Illinois at Chicago**

### Overview



In 2010, The Arc of the United States conducted the Family and Individual Needs for Disability Supports (FINDS) on-line survey with the purpose of better understanding the experiences of family caregivers of individuals with intellectual or developmental disabilities (IDD). This data brief focuses on self-reported outcomes for sibling caregivers of people with IDD. The experiences of sibling caregivers were examined for those living with as well as separately from their brothers and sisters with IDD.

Many siblings provide care and support to their family members with disabilities. The FINDS 2010 survey found that sibling caregivers not living with their brothers and sisters reported better health and lower stress than other sibling caregivers living with their brothers and sisters with IDD. They also reported less loneliness and physical strain. Sibling caregivers living apart more frequently reported that they were able to engage in self-care practices such as having a restful night's sleep, having a social life, and finding time for self-care practices such as exercise.

## Background



Family caregivers are the backbone of supports and services for people with disabilities in the United States. Over 18% of the US population provides supports to a family member with a disability, a chronic illness, or who is aging (National Alliance for Caregiving, 2015). An estimated 85% of the 4.7 million individuals with IDD in the United States are not receiving formal services through their state's IDD agency and are most likely living with and receiving the majority of their support from family members. Half of all individuals with IDD who are receiving formal services live with family and receive supports from their family in addition to paid supports (661,442; Anderson, 2016).

As parents age, siblings increasingly provide supports to their brothers and sisters with disabilities. A survey of siblings of individuals with IDD indicated that 36% of siblings provided at least half of the support required by their sibling with disabilities, and 31% reported that they expected to be the primary source of support for their sibling in the future (as their parents aged) (Easter Seals, 2013). Siblings report that they need support for their caregiving role such as: 1) getting information related to supports and services for the brothers and sisters with disabilities, 2) getting caregiving-related support for themselves, and 3) improving the system of formal supports to better address their needs, including the provision of respite services (Arnold, Heller & Kramer, 2012).

Caregivers often experience both physical and emotional stress on a daily basis due to the effects of caregiving. A review of studies of caregiver outcomes shows that a number of factors are associated with less stress and better mental health outcomes for caregivers (Williamson and Perkins, 2014). For example, older caregivers, caregivers with a family member with fewer support needs, and caregivers who do not live with their family member with disabilities report less stress and better mental health. Caregivers who live with their family member with disabilities and report having fewer unmet needs and using respite more frequently, report less stress and better mental health (Williamson & Perkins, 2014). This highlights the importance of caregiver support. As siblings take on greater caregiving responsibilities, understanding how their experiences with caregiving are similar and different from other caregivers is important when thinking about the best means of supporting sibling caregivers.

The Arc's 2010 FINDS survey provided an opportunity to understand how sibling caregivers report their health status and levels of stress, fatigue and loneliness related to caregiving. It also provided an opportunity to understand the extent to which sibling caregivers are able to meet their own needs, enabling them to continue to provide supports to their family members with IDD.

## Findings



216 sibling caregivers responded to the FINDS survey and 95.1% were white. Siblings living with their brother or sister with disabilities were somewhat more likely to be female (89.1% vs. 85.7%) than siblings not living with their family member. More than half of all caregivers reported being 50 years of age or older (60.9% for siblings living with family member; 53.1% for those not). Family members with IDD tended to be younger than the siblings providing care with most being under the age of 50 (89.4% of those living with their sibling caregiver; 94.9% of those not). Siblings living with their family member were more likely to report that their family member had an ASD (14.4%) than did other siblings (7.6%). Conversely, other siblings were more likely to report that their family member had ID (79.6%) or some other developmental disability (12.9%) compared to sibling caregivers living with their family member (ID, 76.0%; Other DD, 9.6%)\*. Most siblings not living with their family members report providing care 15 or fewer hours per week (81.2%). Conversely, 61.6% sibling caregivers living with their family member report providing care 40 or more hours per week.

In general, sibling caregivers living with their family member reported having more stress and poorer health than other caregivers (Figure 1); 65.3% of siblings caregivers living with their sibling reported

having good or excellent health compared to 82.9% of other siblings. Those living with their siblings with IDD more likely to report that they were very or extremely stressed than did other siblings (43.0 % vs. 21.8%). Both of these differences were statistically significant. Caregivers also reported the extent to which they felt physical strain or fatigue and loneliness, both of these are important because they are risk factors for poor physical and mental health outcomes (Miodrag & Hodapp, 2011) (Figure 2). Sibling caregivers living separately from their sibling with IDD were more likely to report that they didn't experience loneliness (58.2%) or fatigue (31.3%) than did siblings caregivers living with their family member (36.2%; 11.3%). More than half of both caregiver groups reported feeling fatigue and physical strain (siblings living with family member, 62.0%; other caregivers, 56.9%) at least some of the time. More than a third of all caregivers reported feeling lonely some of the time (siblings living with family member, 50.7%; other caregivers; 36.9%).

Sibling caregivers living with and separately from their family member with IDD differed on the extent to which they were more able to engage in self-care practices (Figure 3). Siblings living separately from their family member were much more likely than caregivers living with their family member to agree or strongly agree that they were able to balance work, family and other responsibilities (sibling living separately, 67.1%; siblings living with family member, 36.2%), have an active social life (sibling living separately, 78.5%; siblings living with family member, 36.8%), or have a restful night's sleep (sibling living separately, 70.6%; siblings living with family member, 50.0%). Sibling caregivers living apart from their family member with IDD were also more likely to report that they did not have a problem finding respite (siblings living apart, 64.6%; siblings living with family member, 13.8%). Seven out of ten sibling caregivers living with their family member either agreed or strongly agreed that they did not have enough time to meet their own needs, while the same was true for only 22.5% of siblings living separately from their family member.

## Summary & Discussion



Our analysis of the FINDS survey data shows important differences between siblings that live with their brothers and sisters compared to those that do not. While all of the siblings caregivers were adults, those living with their sibling with disabilities tended to be somewhat older than those not living with their sibling. Overall, the findings show more positive outcomes for sibling caregivers who do not live with their brothers and sisters with disabilities. The caregiving role for siblings that do live with their brothers and sisters with disabilities is likely more demanding, takes more of their time, and have a larger impact on their well-being. These findings reflect the greater support needs among siblings who live with their family members and highlights the need for further research about sibling caregivers.

This also highlights the importance of increasing the capacity of communities to support family caregivers with services such as respite and other caregiver supports so that caregivers have adequate time to meet their personal needs and to practice self-care skills. Sibling caregivers who are able to access supports and services for their sibling with disabilities experience less stress and better health which increases their ability to provide supports for their siblings (Hall & Morano, 2014). As the number of sibling caregivers continues to grow and their caregiving responsibilities increase, more attention should be paid to providing caregiver support to siblings.

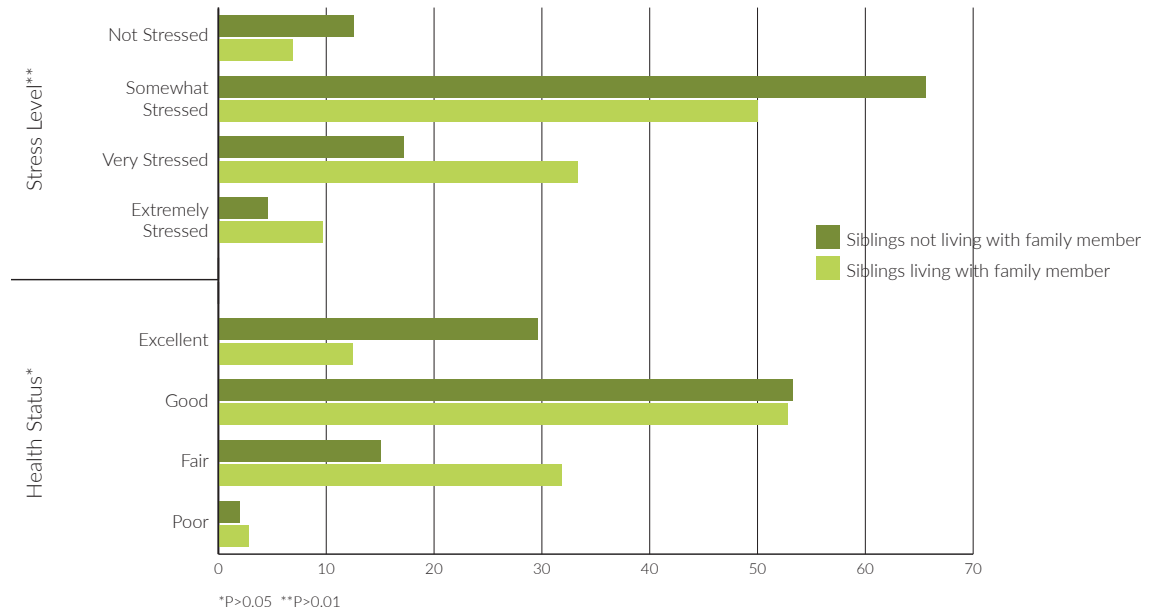
A limitation of our findings is that non-white siblings are not well-represented in this survey. This is an important limitation because other research has shown that white siblings are less likely to be caregivers than are other siblings (e.g., Sonik, et al, 2016).

*\*Footnote: For this analysis if an individual had an intellectual disability along with ASD or some other developmental disability, they were in the ID group. People in the ASD group were only identified as having ASD. People in the other developmental disability group, had neither ID nor ASD. This would include people who had cerebral palsy, for example.*

**Table 1: Demographic Characteristics of Survey Respondents**

	Siblings Living with Family Member (N=72)	Siblings Not Living with Family Member (N=144)
<b>Age of Caregiver</b>		
18-30 years	3.1%	7.5%
31-50 years	35.9%	39.5%
51 and older	60.9%	53.1%
<b>Gender of Caregiver</b>		
Female	89.1%	85.7%
Male	10.9%	14.3%
<b>Race/Ethnicity of Caregiver</b>		
White	95.1%	86.7%
Black	3.3%	3.0%
Other	1.6%	10.3%
<b>Hours per Week Providing Supports</b>		
15 hours of fewer	9.3%	81.2%
15-49 hours	29.1%	15.3%
41-80 hours	22.1%	1.2%
81+ hours	39.5%	2.4%
<b>Disability of Family Member</b>		
ID	76.0%	79.6%
ASD (no ID)	14.4%	7.6%
Other DD	9.6%	12.9%
<b>Level of Disability of Family Member</b>		
Mild	24.3%	15.3%
Moderate	56.3%	45.0%
Severe	19.4%	39.6%
<b>Age of Family Member with IDD</b>		
Less than 10 years	9.4%	16.1%
10-30 years	48.2%	59.8%
31-50 years	31.8%	19.0%
51 years and older	10.6%	5.2%

**Figure 1: Self-Report Health Status and Stress Levels of Siblings and Other Caregivers**



**Figure 2: Caregiver Reports of Fatigue and Loneliness**

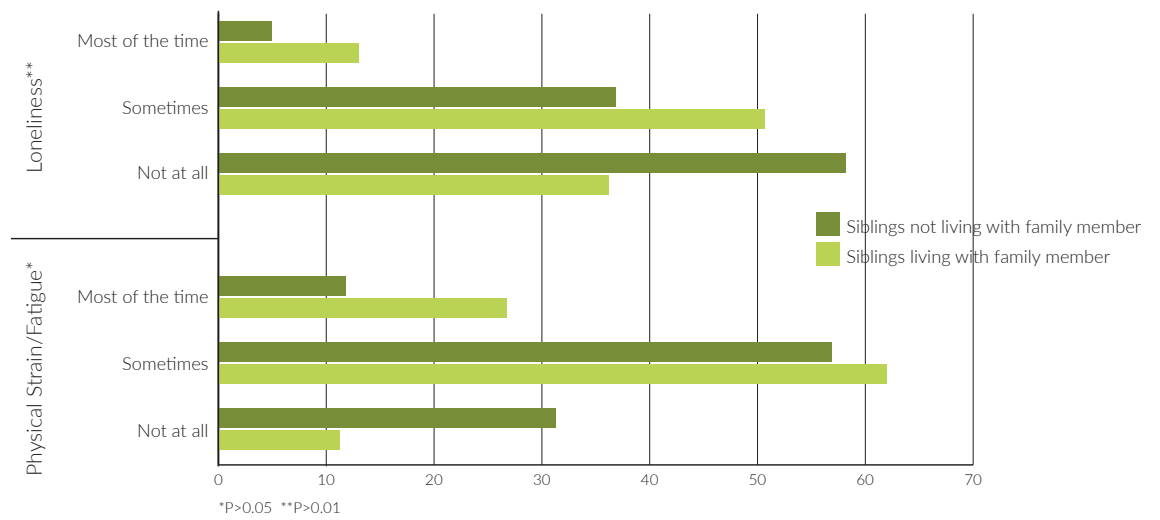
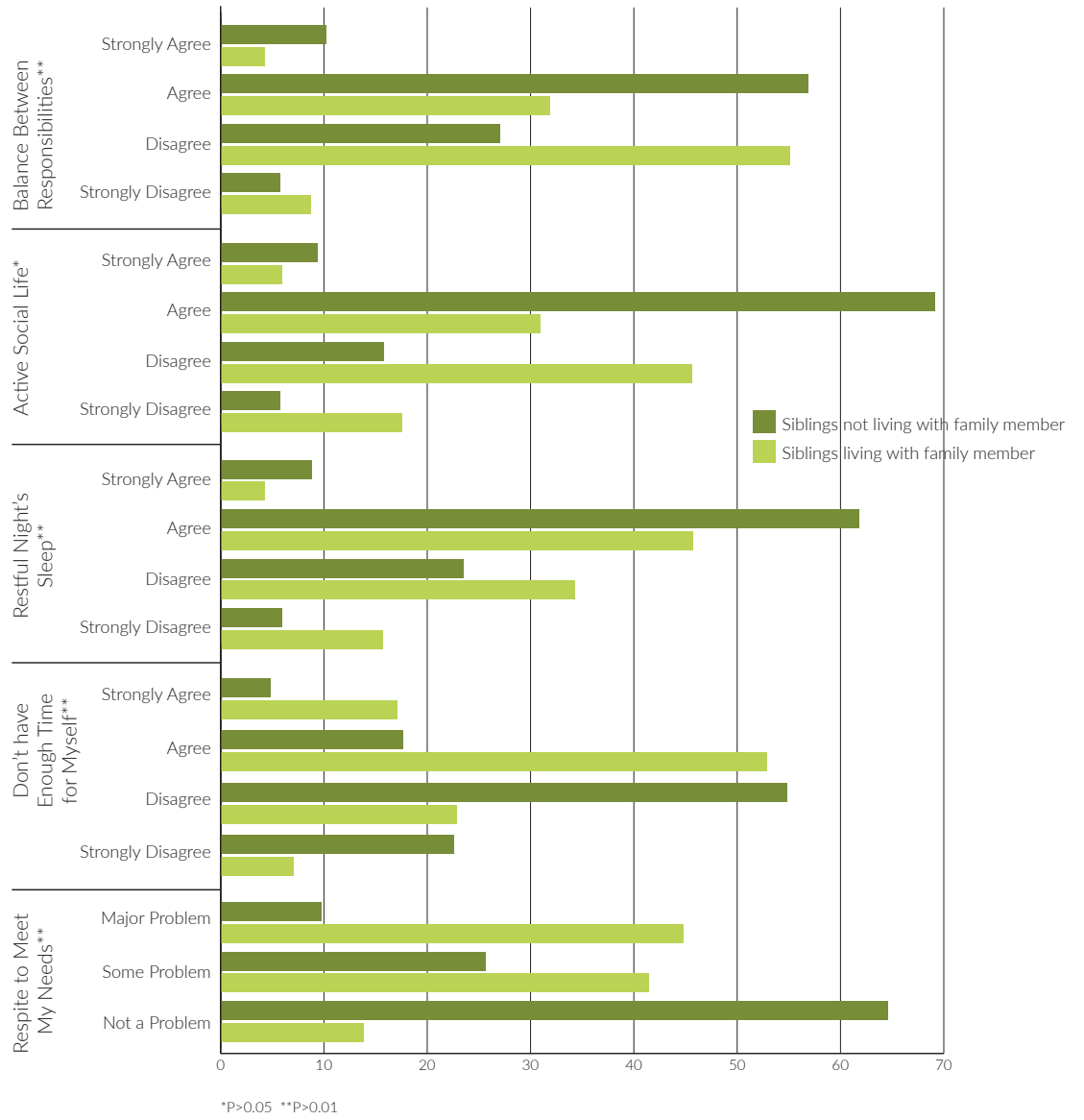


Figure 3: Caregiver Reports of Ability for Self-Care



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