



## Sibling Caregivers Experience Less Choice and Control

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### Overview



For this databrief we looked at the sibling role in long-term care for their family member with intellectual and developmental disabilities (IDD). Our purpose was to assess the choice and control measures for sibling caregivers and their respective family member with IDD to see if they had different experiences with choice and control than other types of caregivers in the survey (primarily parents). We analyzed the data from the National Core Indicators Adult Family Survey completed in 2012-2015. The NCI Adult Family Survey is a mail survey sent to families of adults with IDD who are residing in the home of that family member while receiving services under the auspices of the state Developmental Disabilities agency. 18,728 people responded from the 25 states (for more information about participating states visit [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)). All of the respondents' family members with IDD live in the family home. Of the total respondents, 1,379, or about 7% identified themselves as siblings of people with IDD.

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We found that sibling caregivers who responded to this survey generally reported having less choice and control than did other caregivers. Siblings were also more likely to report lower household incomes, although their ages were similar to other caregivers in this survey. Discussions of aging caregivers often talk about parents as the aging caregivers, but it should be noted that many sibling caregivers are also getting older and more than half of the sibling caregivers responding to this survey were over the age of 55.

## Background



Siblings often have the longest relationships of their lives with each other and many siblings of people with IDD provide critical support and caregiving in their roles (Heller & Arnold, 2010). As people with IDD live longer and outlive their parents, caregiving roles often transition from parents to siblings in families. A review of the literature found that many siblings currently fulfill or anticipate in the future a caregiving role for their brothers/sisters with disabilities (Heller & Arnold, 2010). Some important influences on expectations about future care include gender, number of siblings in a family constellation, and emotional attachment in determining future care for their sibling with disabilities. Often women fulfill the primary care role over men (Hodapp, Urbano, & Burke, 2010). Also, among families with numerous siblings, often one main sibling, typically the oldest sister, were more involved in primary care (Heller & Arnold, 2010). Moreover, siblings who are more emotionally close to their brothers/sisters with disabilities will be far more likely to accept primary care roles (Burke, Taylor, Urbano, & Hodapp, 2012). A recent study on sibling caregiving from the perspective of adults with disabilities found that the more frequently the person with disabilities was in contact with their sibling, the stronger the relationship quality and the more likely the sibling provided caregiving (Burke, Lee, Arnold, & Owen, 2016). However, while many siblings anticipate fulfilling future roles, siblings often do not feel prepared to take on these roles (Arnold, Heller, & Kramer, 2012). Siblings are often not included in the future planning process (Arnold, Heller, & Kramer, 2012; Heller & Kramer, 2009) where families discuss and make decisions related to the future services and supports for family members with disabilities including, but not limited to living situations, service/healthcare coordination, and financial planning.

**MANY SIBLINGS CURRENTLY FULFILL OR ANTICIPATE IN THE FUTURE A CAREGIVING ROLE FOR THEIR BROTHERS AND SISTERS WITH DISABILITIES.**

In this report we describe sibling caregivers based on age, income and race of the sibling with disabilities (race of caregivers is not available in this dataset). We also examined how siblings perceive their ability to have choice and control over the services used by their family member. These included choice of service provider; having control over resources; and choice of case manager or service coordinator.

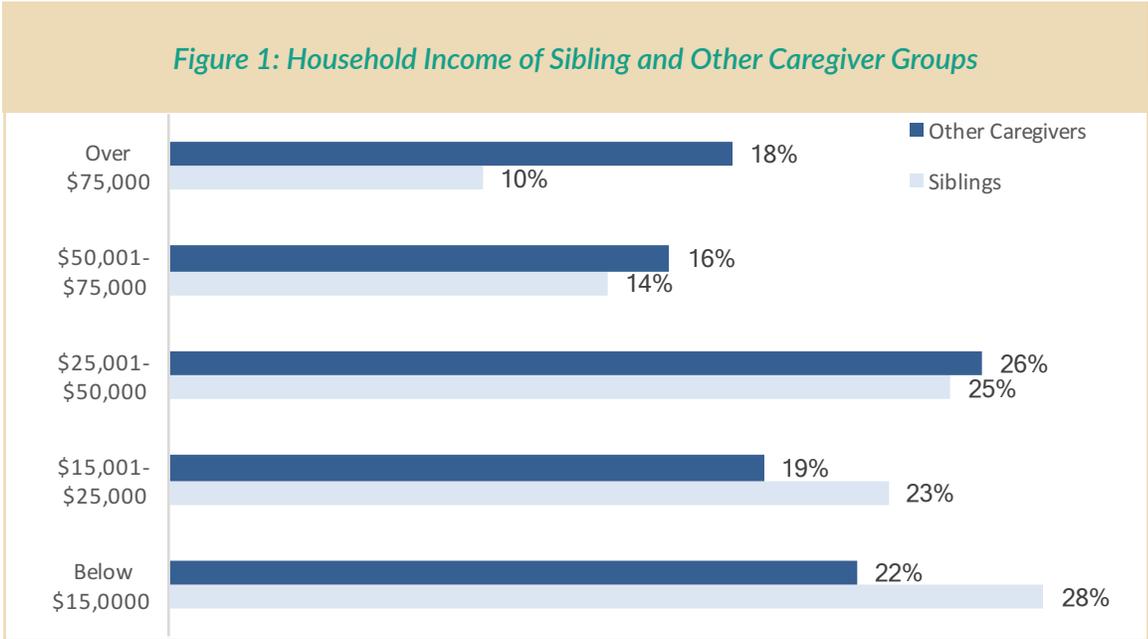
## Findings



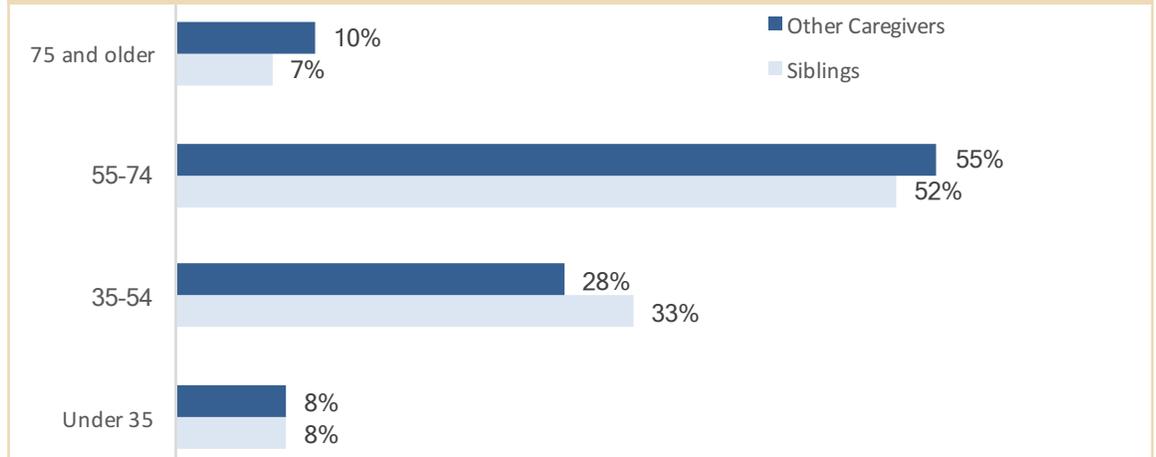
Of the siblings and families that were surveyed, 76% of siblings make less than \$50,000 per year with multiple people in the household as compared to 66% of other caregivers. Siblings were also much more likely to report household incomes of \$15,000 or less as compared to other caregivers (28% vs. 22%). These findings are consistent with data from the Survey

of Income and Program Participation (SIPP) that show sibling caregivers are more likely to experience financial hardship (Sonik, Parish, & Rosenthal, 2016). Figure 1. Most respondents reported that they are the primary caregivers (Sibling, 86%; Other Caregivers, 96%). The majority of both caregiver groups responding to this survey were 55 and older (siblings, 59%; other caregiver, 65%) (given that this is a survey for adult recipients of services the age of the caregivers is not surprising). Figure 2. The NCI family survey does not ask caregivers about their race, however, we do report on the race of the family members with disabilities. The sibling caregiver group was much more likely to report that their sibling was Black (27% vs. 16%) while other caregivers were more likely to report their family member as being White (75% vs 64%). The study by Sonik, Parish, and Rosenthal (2016) also found sibling caregivers were more likely to be Black. Both groups reported the same other race 9% of the time. About 12% of the sibling caregivers reported a Hispanic or Latino background as did about 13% of other caregivers.

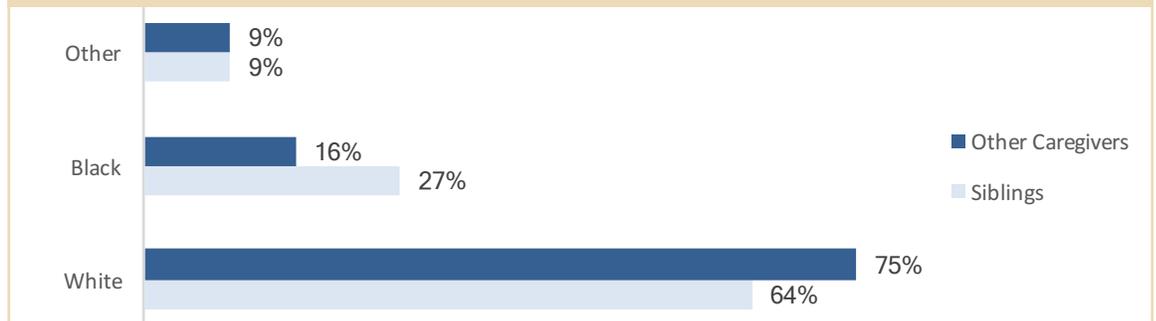
We looked at the extent to which sibling caregivers report having the same choice and control over services for their sibling as other caregivers report. T-tests were used to see if the differences between groups were statistically significant. Although few people in either group report being able to choose a case manager, siblings were even less likely to report choosing a case manager (Sibling, 24%; Other Caregiver, 26%). Less than half of both caregiver groups reported that they could always choose the support worker for/with their family member (Sibling, 44%; Other Caregiver, 45%). The sibling caregiver group was also less likely to report being able to always choose an agency or provider (Sibling, 54%; Other Caregiver, 56%), having control or management over support workers (Sibling, 44%; Other Caregiver, 56%), deciding how allocated money was spent (Sibling, 43%; Other Caregiver, 48%), and having enough information to make spending decisions, if they did make decisions about how allocated money was spent (Sibling, 74%; Other Caregiver, 82%). Figure 4. The differences between these groups were statistically significant in each of the areas examined.



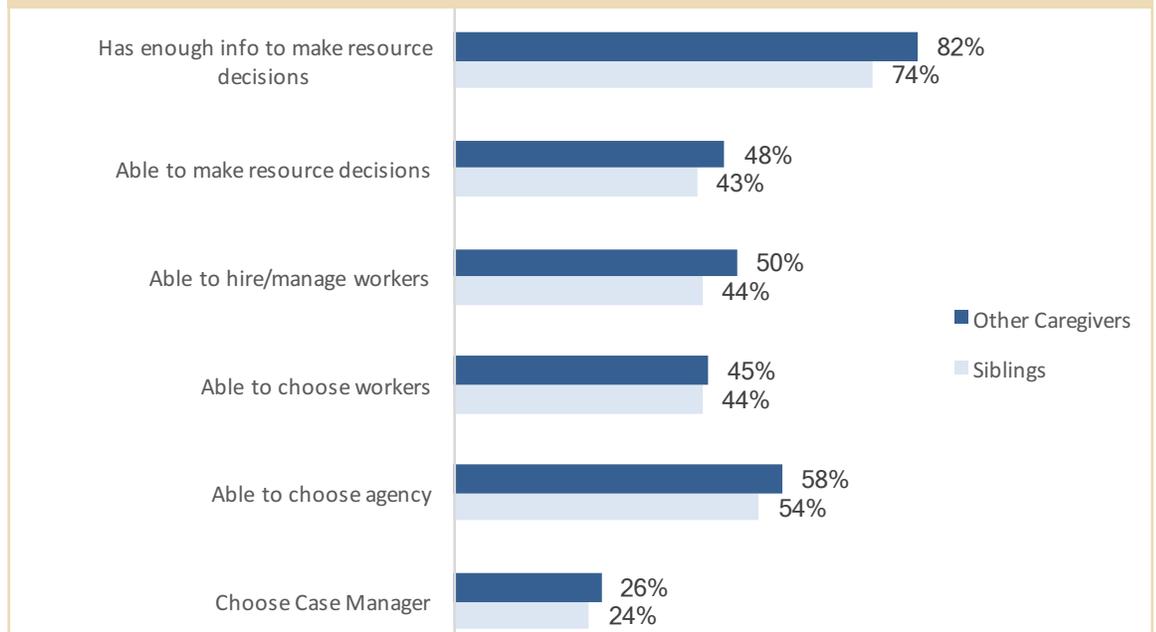
**Figure 2: Age of Sibling and Other Caregivers Groups**



**Figure 3: Race of Family Member with Intellectual or Developmental Disabilities**



**Figure 4: Sibling and Other Caregivers Experiences with Choice and Control\***



\*All differences statistically significant at the 0.05 level

## Summary



Overall, sibling caregivers in this study are worse off than other family caregivers both economically and with regard to choice and control. Sibling caregivers make less than other caregivers and there is likely a financial impact for these siblings in their role. Additionally, sibling caregivers were even less likely than other caregivers to report having choice and control over services and resource allocations, despite the majority reporting that they were the primary caregiver. Although the majority of people with IDD still live in the home of their parents, with transition of care falling to younger generations as parents age it will be critical that the future planning process includes siblings. This is particularly important since many siblings have either assumed or are poised to assume primary caregiving duties from aging parents. This indicates a need to pay more attention to sibling caregivers and invest more in supporting siblings of people with IDD in their caregiving roles.

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