



Sibling Caregiver Experiences with 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). None of the respondents' family members with IDD live outside of the family home. Of the total respondents, 1,379, or about 7% identified themselves as siblings.

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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 more than half of the sibling caregivers responding to this survey were over the age of 55.

Background



Siblings often anticipate that they will fulfill future caregiving roles for their brother/sisters with disabilities. The reason for these changes include the transition of care due to an aging population, a transition to community directed services and deconstruction of the Intermediate Care Facility (ICF) model of care, and a societal shift in the sibling population based on the emotional connections to their brother or sister. According to the Sibling Leadership Network (2013), currently 60 percent of siblings expect to become the primary care giver. Some important influences on expectations about future care include female vs. male siblings in future care, lone vs. multiple siblings, and emotional attachment or family dynamics in determining future care for their sibling with disabilities. Often females fulfill the primary care role over males and families with more siblings often are more involved in primary care. Moreover, family members who are more emotionally/physically attached to their siblings will be far more likely to accept primary care roles. Currently, 19% of siblings are expecting to live with their brother/sisters. However, while many siblings anticipate fulfilling future roles, siblings are often not included in the future life-planning process which includes, but is not limited to habilitation, service/healthcare coordination, and financial planning.

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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%). 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 (Siblings, 27%;

Other Caregiver,16%) while other caregivers were more likely to report their family member as being white (Siblings, 64%; Other Caregiver, 75%). 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.

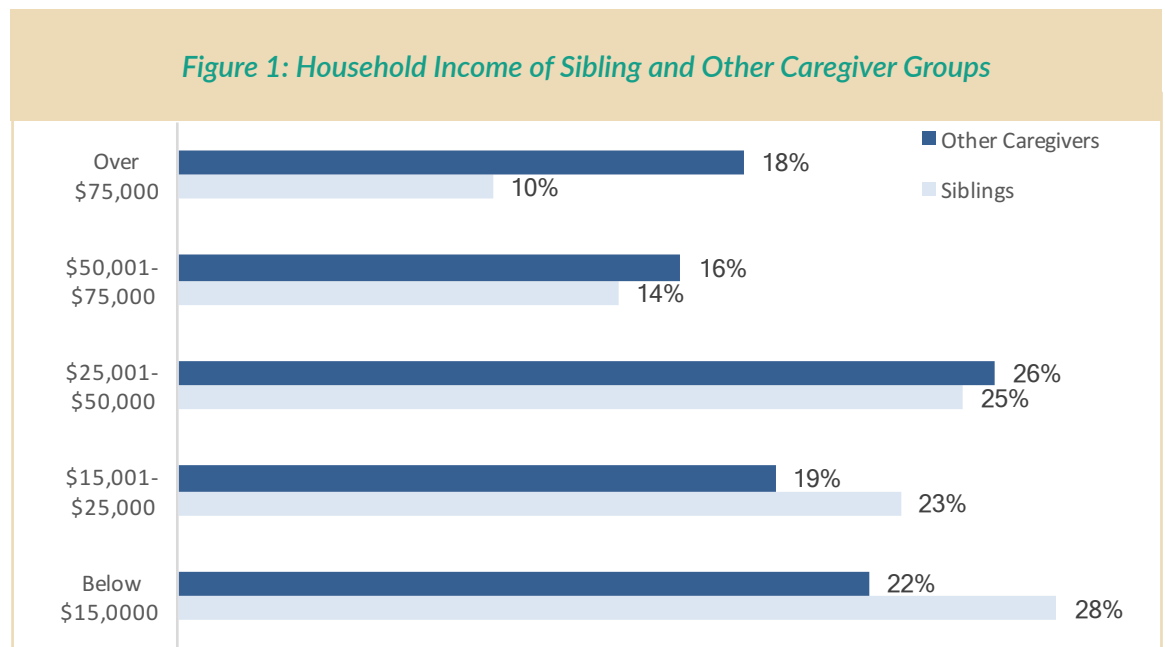


Figure 2: Age of Sibling and Other Caregivers Groups

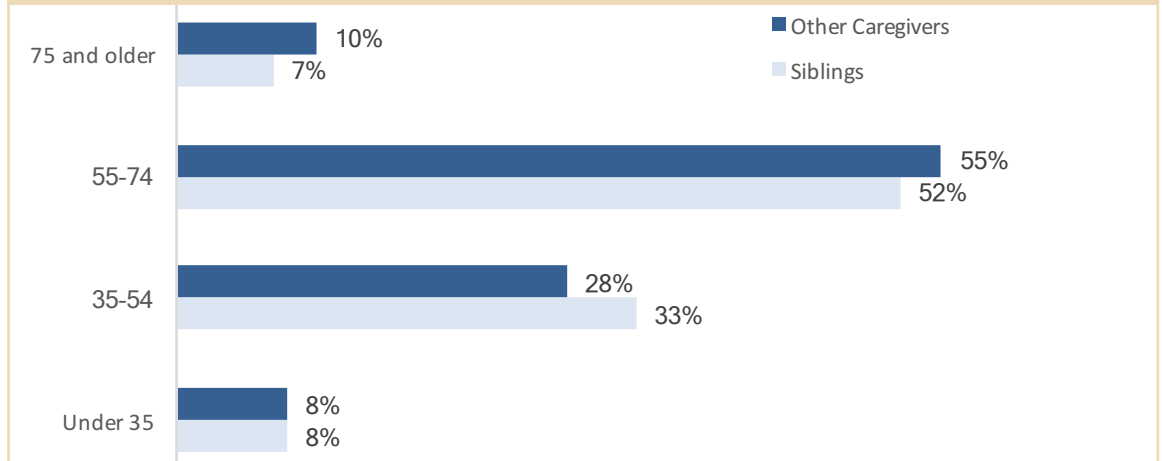


Figure 3: Race of Family Member with Intellectual or Developmental Disabilities

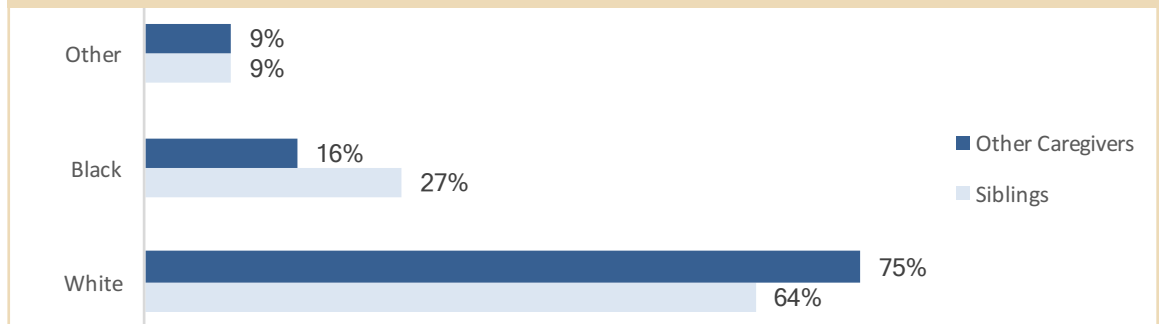
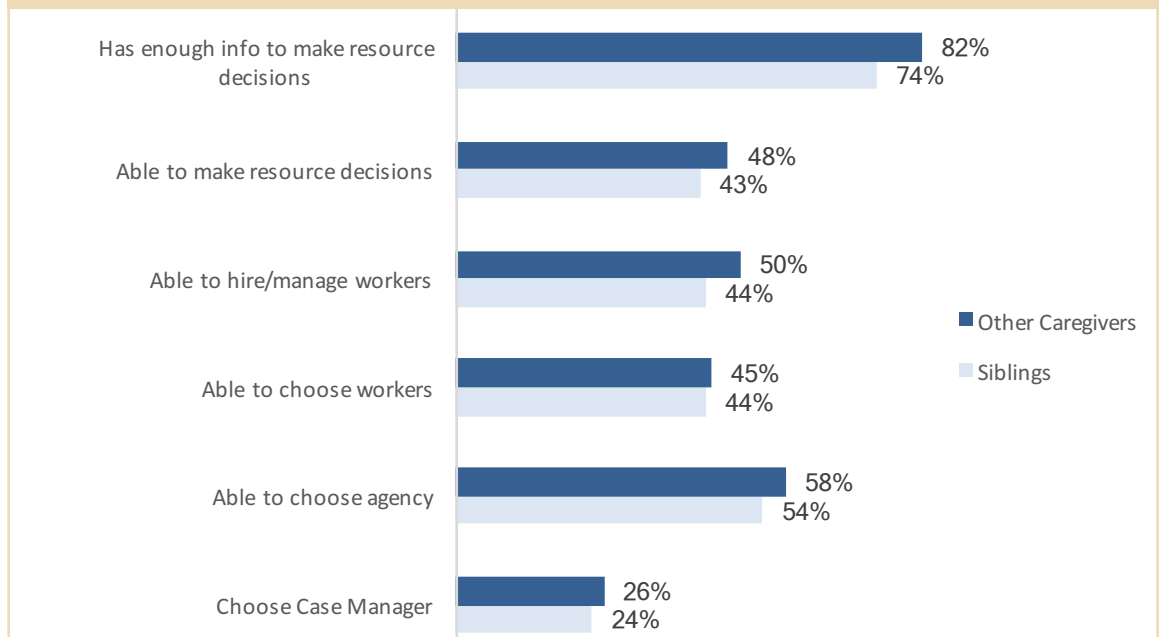


Figure 4: Sibling and Other Caregivers Experiences with Choice and Control*



Summary



Overall, the families that completed this survey indicated that they do not feel choice and control are an integral part of their respective family member's care. Sibling caregivers were even less likely 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 have either assumed or are poised to assume primary caregiving duties from aging parents.

WITH TRANSITION OF CARE FALLING TO YOUNGER GENERATIONS AS PARENTS AGE IT WILL BE CRITICAL THAT THE FUTURE PLANNING PROCESS INCLUDES SIBLINGS.

References



¹. Sibling Leadership Network. (2013). Young siblings of individuals with intellectual and developmental disabilities. Retrieved from: <http://siblingleadership.org/research>.

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