



Family Caregivers of Family Members with IDD Differ from Other Caregivers in the Kinds and Duration of Supports They Provide

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Overview



In 2017, the Research and Training Center on Community Living (RTC/CL) at the University of Minnesota and The Arc of the United States (The Arc) conducted an online survey, the *Family and Individual Needs for Disability Supports (FINDS)* survey. The purpose of *FINDS* is to better understand the experiences of families who provide supports to a family member with intellectual and developmental disabilities (IDD). In this data brief, we compare caregiving experiences of family caregivers for adults with IDD with those of caregivers who responded to the *Caregiving in the U.S. (CUS)* survey in 2015 in order to better understand the experiences of caregivers of family members with lifelong disabilities compared to the experiences of caregivers of those who are aging or have acquired disabilities in adulthood. There were some important differences between the groups, including the duration of caregiving and the types of supports provided.

Background



Nearly 3,400 caregivers representing all states, the District of Columbia, Puerto Rico and Guam participated. The number of people responding was large and provides important information about the experiences and outcomes of family caregivers of individuals with IDD in the United States (U.S.). However, *FINDS* is an online convenience survey and the sample

is not reflective of the racial and economic diversity of the nation. This brief compares family caregivers of adults with IDD to caregivers of adults in the Caregiving in the U.S. survey. There were 2,068 FINDS participants who supported an adult family member with IDD.

The Caregiving in the U.S. survey was conducted in 2015 (National Alliance for Caregiving, 2015). It was an online survey conducted with 1,248 family caregivers. For more information about the Caregiving in the U.S. survey, visit caregiving.org/caregiving2015. For this data brief, we selected the 562 participants who were categorized as “higher-hour” caregivers who provided support to their family member 21 hours or more a week.

Findings



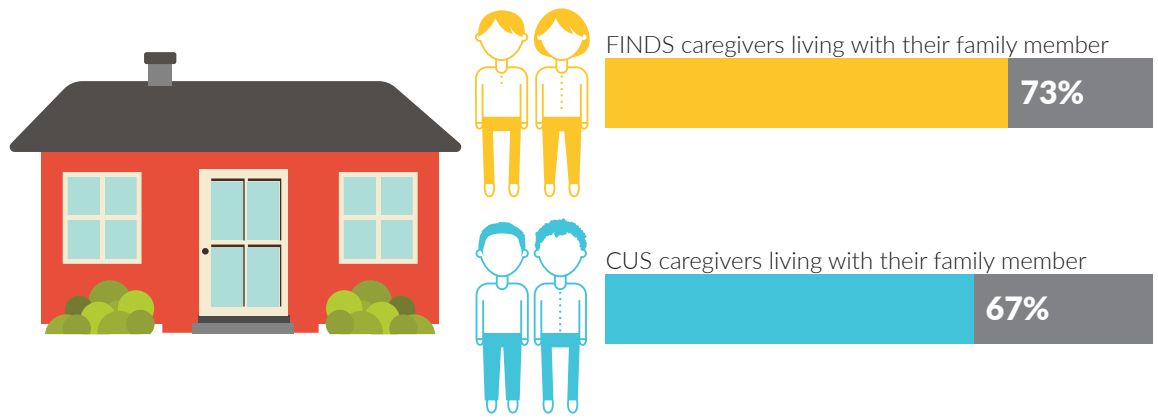
Demographics

Caregiver characteristics. FINDS caregivers were older than Caregiving in the U.S. (CUS) caregivers (62% vs. 33% between the ages of 50-64; 14% vs. 29% younger than 50; and 25% vs. 38% 65 years and older; see Table 1). More FINDS participants reported being female (88% vs. 62%); however, CUS participants were more racially diverse. Half (50%) of the CUS caregivers identified as white, followed by Latino (17%; FINDS, 2%), black (15%; FINDS, 4%), and other (18%; FINDS 3%). The relationship between the caregiver and care recipients differed between the two surveys. More than 8 of 10 (85%) FINDS participants were parents; 8% were siblings; 6% were some other relationship; 1% were spouses or partners, and, less than 1% were children of the adult with IDD. Conversely, only 6% of CUS caregivers were parents; 48% were children of the person receiving supports (includes in-laws); 24% were spouses or partners; 4% were siblings (includes in-laws); and 18% had some other relationship with the person they were supporting. Three-quarters (73%) of FINDS caregivers lived with their family member as did 67% of CUS caregivers.

Family member characteristics. The FINDS care recipients were younger with 92% reported to be 49 and younger, compared

Table 1: Demographic Characteristics of Caregivers and Care Recipients

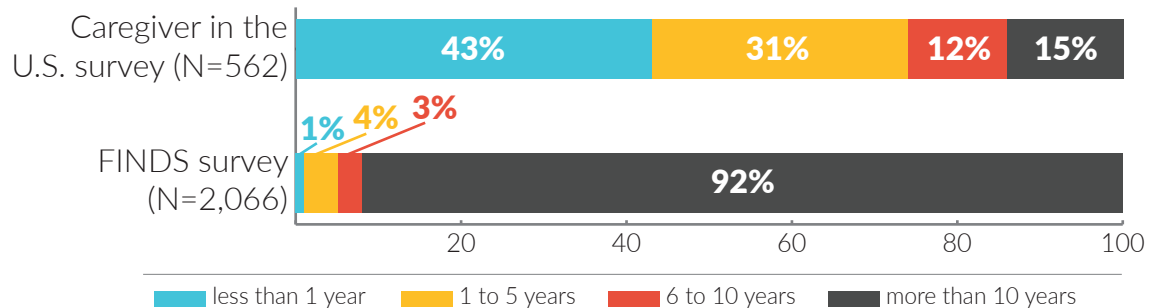
	FINDS	Caregiving in the U.S.
Caregivers	N=2,068	N=562
Age		
18-49	14%	29%
50-64	62%	33%
65+	25%	38%
Gender		
Male	12%	38%
Female	88%	62%
Race		
White	89%	50%
Black	4%	15%
Latino	2%	17%
Other	3%	18%
Relationship		
Spouse/ Partner	1%	24%
Parent	85%	6%
Child	0.3%	48%
Sibling	8%	4%
Other	6%	18%
Lives with Family Member Care Recipient	73%	67%
Age		
18-49	92%	12%
50 and older	9%	88%
Gender		
Male	60%	38%
Female	40%	62%



to just 12% of CUS care recipients. They were also more likely to be male (60% vs. 38%). Most of the caregivers in the CUS were supporting family members due to long-term physical conditions (64%), memory problems (25%), emotional/mental health conditions (21%), behavioral challenges (9%), or IDD (6%).

Supports Provided

Caregiving duration. FINDS participants reported providing supports to their family member with disabilities for a longer time than CUS caregivers. Nine out of ten (92%) FINDS caregivers had been providing support for more than ten years. Four of ten (42%) CUS caregivers had been caring for their family member for less than one year.



Types of supports provided¹. Activities of daily living (ADLs) are activities related to day-to-day functioning including tasks such as grooming or eating. FINDS caregivers were, on average, somewhat less likely than CUS caregivers to provide ADL supports (2.4 vs 2.6 ADLS out of a total 6 ADLs). Difficulty providing supports was measured on a scale of 1 (not at all difficult) to 5 (very difficult) FINDS caregivers were, on average, more likely to report greater difficulty with these tasks than were CUS caregivers (3.1 vs. 2.6). Instrumental activities of daily living (IADLs) are activities such as money management, shopping, or arranging outside supports. Caregivers in both groups were more likely to

¹ ADLs include helping getting in and out of bed/chairs, getting dressed/undressed, getting to and from the toilet, bathing/showering/grooming, providing assistance with toileting or incontinence, and assisting with eating. IADLs include giving medications, managing finances, doing errands or grocery/other shopping, doing simple home upkeep preparing simple meals or arranging for meals, and arranging for outside services. The FINDS included additional ADL and IADL supports that were not included in the CUS survey that are not included in this analysis for purposes of comparability.

provide IADL supports than ADL supports. Out of the six IADL supports identified, FINDS caregivers assisted with an average 5.3, and CUS caregivers assisted with an average 5.5.

CUS caregivers assisted with medical or nursing tasks more than FINDS caregivers (85% vs. 9%). However, FINDS participants reported greater difficulty with these tasks than CUS caregivers (2.6 and 2.4, respectively). FINDS caregivers reported advocating for their family member (93%), monitoring their family members' condition to adjust care/supports (90%), and communicating with healthcare and other professionals on behalf of their family member (95%) more than CUS caregivers (64%; 82%; 83%, respectively).

Summary & Discussion



Caregivers of family members with disabilities or of aging family members provide a wide range of supports from help with daily living to performing medical tasks. In this brief we were interested in how caregiving experiences differ for caregivers of people with IDD compared to caregivers of people across disabilities and caregiver needs. Caregivers in the FINDS and the CUS reported providing some ADL and IADL supports. Differences across the two groups were apparent in the other kinds of supports caregivers provided. CUS caregivers reported assisting with more medical tasks FINDS caregivers provided more advocacy supports, monitoring of their family member's condition, and communication with professionals. FINDS caregivers also lived with their family members and provided care for longer periods than CUS caregivers. These differences, without doubt, are related to differing roles the caregivers played in the lives of their family members. FINDS caregivers were mostly parents supporting an adult child with IDD, while CUS caregivers were children or spouses of a person needing supports due to aging.

Caregivers provide important, too often unrecognized, supports to their family members with disabilities and aging. They are the backbone of the long-term supports and services system in the United States. As the population ages, the supports that families provide is going to become increasingly important and addressing the needs of family caregivers is paramount for them to be successful. However, caregivers' experiences vary greatly depending on the caregiver's relationship with their family member and the reason their family needs additional supports. Caregiver supports need to be flexible in order to meet the needs of all caregivers across the lifespan.

References



National Alliance for Caregiving. (2015). *Caregiving in the US*. AARP; Bethesda, MD: The National Alliance for Caregiving.

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