



60% of family caregivers provide more than 40 hours of support per week

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

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

Amie Lulinski, PhD, The Arc

Overview



The 2010 Family and Individual Needs for Disability Supports Survey (FINDS) conducted by The Arc (2011), shows that family caregivers play a critical role in providing supports to individuals with intellectual and developmental disabilities (IDD). This databrief describes the kinds and amount of supports provided by families to individuals with IDD living in their family home. Caregivers provided an average of nine different kinds of support and more than half of all caregivers reported providing these supports more than 40 hours per week. More than half of caregivers in this survey reported being aged 50 or older, highlighting the critical need to start planning for a future when aging caregivers are no longer able to continue providing significant amounts of support for their family members.

Background



According to the National Alliance for Caregiving (2015), 18.2% of the US population provides supports to a family member with a disability, a chronic illness, or who is aging. These caregivers provide an average of 24.4 hours of care per week with 23% providing more than 40 hours of care per week. An estimated 85% of the 4.7 million individuals with IDD in the United States are not receiving services through their state's IDD agency and are most likely living with family members (based on numbers of individuals with IDD known to state developmental disability agencies: Anderson, 2016). Roughly, half (48%, n = 661,442) of all individuals with IDD who are receiving services live with family (Anderson, 2016). The

role of family caregiving for individuals with IDD, unlike with many other groups represented in the National Caregiver Action Network survey, is lifelong which makes families a critical piece of the support picture for individuals with IDD.

In 2010, The Arc of the United States conducted a national internet survey that aimed to capture the perspectives of family caregivers of people with intellectual or developmental disabilities (IDD). Nearly 5,300 family respondents participated in the “Family and Individual Needs for Disability Supports” (FINDS) survey. FINDS asked caregivers questions about services received, quality of those services, supports needed, caregiver provided supports and about caregiver outcomes. This data brief focuses on the 3,386 survey participants who reported that their family member with disability lived in the family home and the kinds and amount of supports they provide to their family members with IDD. The FINDS survey was an on-line convenience sample, and, therefore, the results may not reflect the diversity of family caregivers in the United States.

Findings



The family caregivers that responded to the 2010 FINDS survey were predominately white (90.3%), female (89.2%), older than 50 (53.8%) and were married/partnered (76.6%). Most of the survey respondents (83.2%) were parents. Survey participants reported most often that their family member was between 10 and 30 years of age (55.5%) and had moderate levels of disability (52.1%). Because the respondents to this survey were not reflective of the diversity of the US population, caregivers from different backgrounds may have different experiences with providing supports for their family member.

Survey participants were asked to report whether or not they provided 13 different kinds of support for their family member with disabilities. The average number of supports provided by family caregivers was eight, with 12 supports reported by the greatest percentage of survey participants (22%). Figure 1 shows the percentage of survey participants that reported providing this type of support for their family member. Transportation and emotional support were the most frequently mentioned kinds of support given, although more than half of survey participants reported that they provided support in 12 of the categories. Nearly sixty percent (59.8%) of family caregivers reported providing more than 40 hours of care per week for their family member (see Figure 2.)

Summary & Discussion



Data tell us that families are the backbone of the community-based support system in the United States as family caregivers provide a significant amount of the supports for people with IDD. Additionally, these caregivers are typically older and have a parental relationship with the person to whom they provide care (Ryan, et al, 2013). The amount of caregiving hours and tasks provided, coupled with other obligations such as employment or providing care to other family members (e.g., aging parent, spouse, or other children), may lead to the high stress rates often reported by caregivers (Williamson & Perkins, 2014). Williamson and Perkins (2014) note that given the reliance on caregivers to provide supports, greater attention on the needs of caregivers is critical to prevent “physical or mental health setbacks” that may lead to the necessity of out-of-home placement for the individual with IDD. Supporting caregivers with their current caregiving roles and assisting them in planning for future support needs when they are no longer able to provide care are critical policy issues that need further attention in a support system based on providing supports in community settings. Efforts can be as simple as providing caregivers with information and support to begin future planning (The Arc, 2017).

Figure 1: Kinds of Support Given Reported by Family Caregivers (n = 3,386)

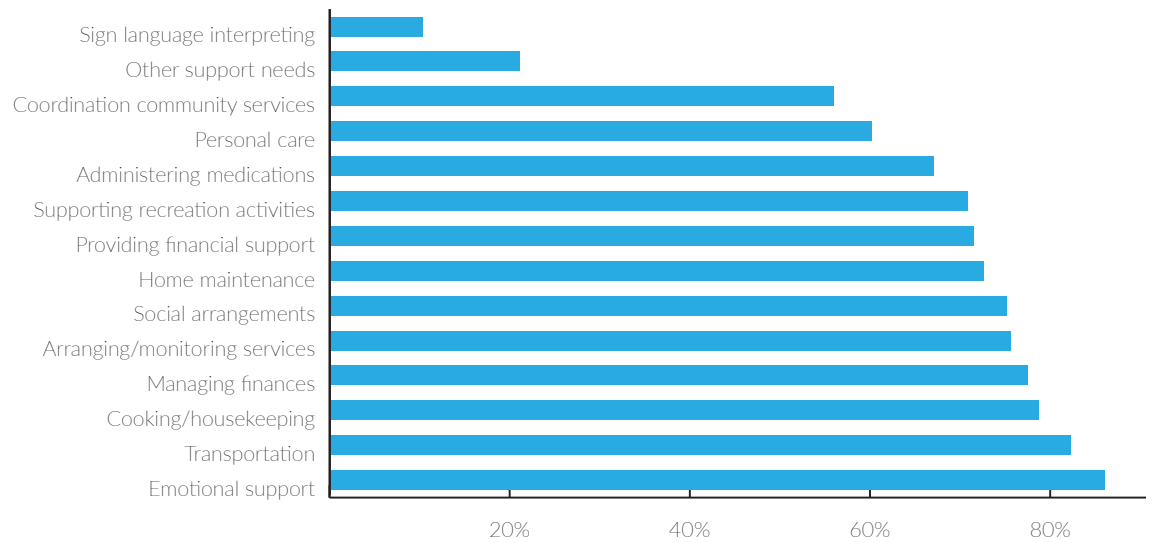
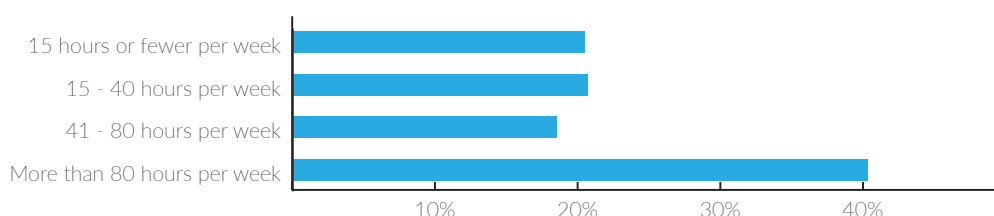


Table 1: Demographic Characteristics of Survey Respondents

Caregiver characteristic	Percent of respondents
Age (n=2,019)	
18-30 years	2.1%
31-50	44.0%
51 and older	53.8%
Relationship (n=4,662)	
Parent	84%
Other family member	11%
Non family member	5%
Gender (n=1,990)	
Male	10.8%
Female	89.2%
Race/Ethnicity (n=1,992)	
White	90.3%
Black	4.5%
Latino	3.2%
Asian	1.4%
American Indian	0.7%
Marital Status (n=1,962)	
Not married	23.4%
Married/partnered	76.6%
Age of family member with disabilities (n=2,702)	
Under 10 years	18.4%
10-30 years	55.5%
31-50 years	19.6%
51 and older	6.5%
Level of disabilities (n=2,656)	
Mild	19.5%
Moderate	52.1%
Severe	28.5%

Figure 2: Hours per week caregivers spent providing Supports



References



Anderson, L.L., Larson, S.A., Kardell, Y., Taylor, B., Hallas-Muchow, L., Eschenbacher, H.J., Hewitt, A.S., Sowers, M., & Bourne, M.L. (2016). Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

The Arc (2017). Center for Future Planning. <https://futureplanning.thearc.org/pages/learn/future-planning-101>

The Arc (2011). Family and Individual Needs for Support survey: Technical report. <http://www.thearc.org/FINDS>

National Alliance for Caregiving & AARP Public Policy Institute (2015). Research Report: Caregiving in the US. http://ww1.prweb.com/prfiles/2015/06/03/12765231/2015_CaregivingintheUS_Final%20Report_WEB.pdf

Ryan A., Taggart L., Truesdale-Kennedy Y. M. & Slevin E. (2013) Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. International Journal of Older People Nursing doi: 10.1111/opn.12021

Williamson, H. J., & Perkins, E. A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Outcomes associated with US services and supports. Intellectual and Developmental Disabilities, 52(2), 147-159.

The contents of this databrief were developed for the University of Illinois at Chicago Family Support Research and Training Center (FSRTC) under a grant from the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant # 90RT50320-01-00 and through cooperative agreements from the U.S. Department of Health and Human Services, Administration on Community Living, Grants #90DN0291-04-01 (primary), #90DN0297-03-01 and #90RT5019-01-04. Contents do not necessarily represent the policy of the Department of Health and Human Services (DHHS), ACL or NIDILRR policy and you should not assume endorsement by the Federal Government.



This databrief was developed in partnership with **FISP (Supporting Individuals and Families Information Systems)**.