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Employment outcomes and paid leave for caregivers of adults with intellectual or developmental disabilities

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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/or developmental disabilities (IDD). In this brief, we look at the work experiences and outcomes of caregivers of adults with IDD and the need for paid leave policies. This brief examines a subsample of 807 caregivers of adults IDD, ages 18 and older, from the *FINDS* survey.

Background

Estimates are that more than 40 million people in the United States (U.S.) provide informal care to aging relatives or relatives with disabilities (Cynker & Mendes, 2011; Bureau of Labor Statistics, 2017). Caregivers provide an average of 18 hours of care per week amounting to the equivalent of \$470 billion in care provided (Reinhard et al., 2015).

An estimated 2 million adults with IDD ages 22 and older live in the U.S. (Larson et al., 2018). About 900,000 adults with IDD are known to state developmental disabilities agencies, either because they are receiving some sort of support or service, such as Medicaid-funded Long Term Supports and Services (LTSS), or because they are waiting for supports (Larson et al., 2018). Long-term supports and services include services such as personal care assistance, in-home supports, or employment supports. 58% of individuals receiving LTSS live in the home of a family member, meaning that informal family support is important even for people receiving LTSS (Larson et al, 2018). Families are typically the main sources of support for individuals who need supports but are not served by the state LTSS system. Caregiving can have a negative effect on caregivers' employment, such as arriving to work late or leaving early, reducing work, or leaving the workforce altogether (Michaud et al., 2010; National Alliance for Caregiving, 2015).

Findings

Demographics. Caregivers in this *FINDS* survey subsample were most likely to be female (90%) and white (88%). The average age of caregivers was 58 years, ranging from 22 to 86 years of age. 72% of caregivers lived with their family member with IDD, while 28% did not. Caregivers were parents (85%), siblings (8%), or had some other relationship such as grandparents, aunts/uncles, or friends of the person being supported (7%). More than half (54%) of caregivers provided 40 or more hours of support per week, while 32% of caregivers provided support to their family for 20 or fewer hours per week.

The family members with IDD were more likely to be male (61%) and ranged in age from 18 to 89. The average age was 31. They were most likely to report being white (86%), followed by Latino/a (4%) and black (4%). Four in 10 caregivers reported that their family member had intellectual disability (37%). About one-fourth reported that their family member had both intellectual disability and autism spectrum disorder (25%). 20% had autism spectrum disorder only, and 17% had some other developmental disability.

Caregiver health and stress. 35% of caregivers reported that their health was very good or excellent; most reported that it was good (37%) or fair (21%). Half of caregivers reported the caregiving responsibilities had made their health worse (51%) and that they were very or extremely stressed (66%). 63% reported that they had a problem finding time to care for their own health issues. Caregivers also reported that being able to pay for support for their family member was somewhat of a problem (39%) or a major problem (31%).

Figure 1: Health Status Reported

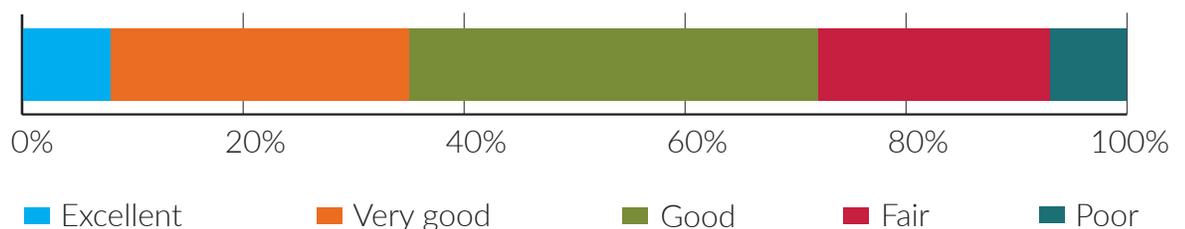
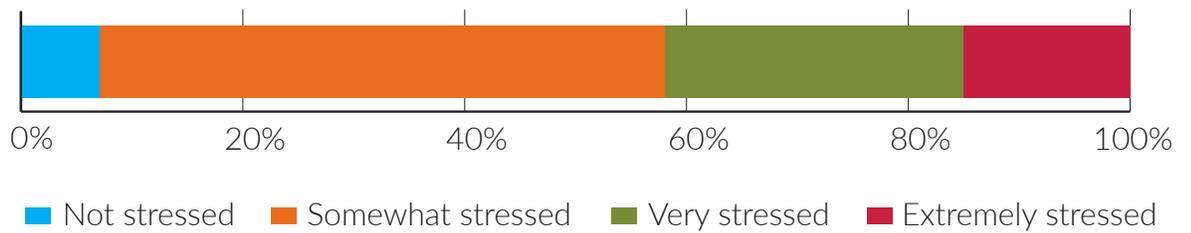
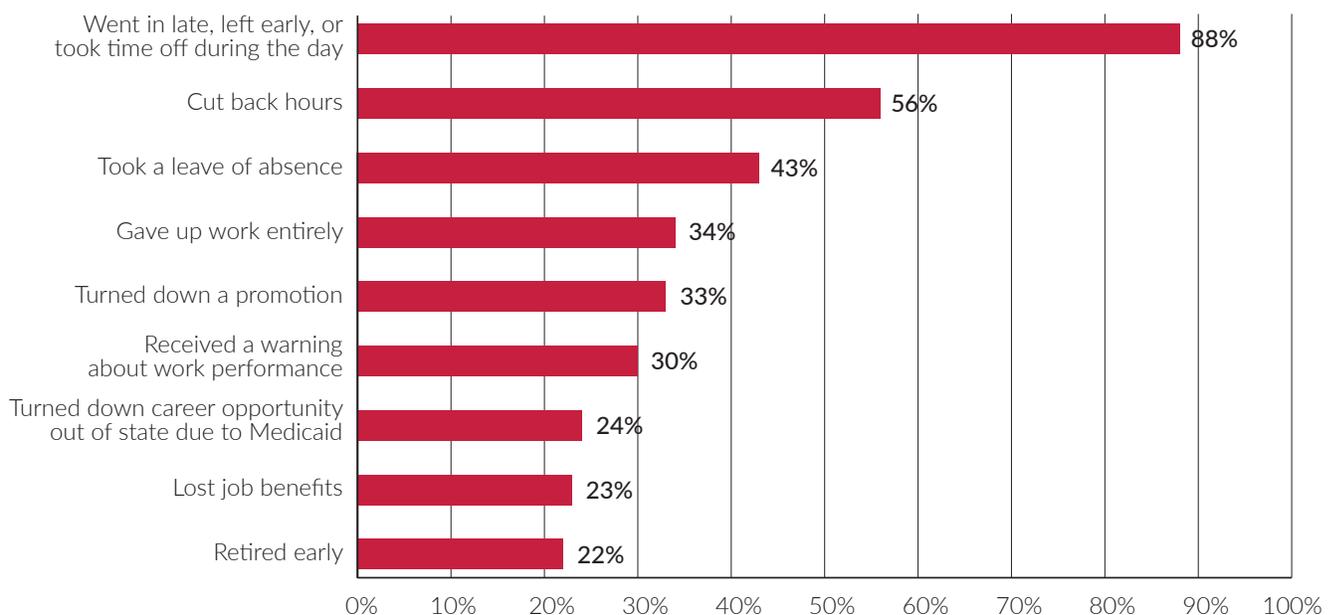


Figure 2: Stress Levels Reported



Employment and employment-related outcomes. Caregivers were asked if they had worked in the previous 12 months. Most of the caregivers reported being employed, either by someone else (49%) or self-employed (13%), working an average of 33 hours in addition to the supports they provided for their family with IDD. 56% of caregivers who worked agreed that their role as a caregiver interfered with work. 70% reported that adjusting their work schedules and meeting their work responsibilities was a problem. A significant majority of caregivers (88%) reported that they had gone into work late, left early, or took time off during the day to meet their caregiving responsibilities. Somewhat more than one half of caregivers who were currently employed or who had been employed in the previous 12 months (56%) reported cutting back hours; many took a leave of absence (43%), 33% gave up work entirely due to caregiving responsibilities, and 22% retired early. Compounding the challenges of meeting work and care responsibilities are the challenges of finding supports and services while caregivers work. 28% of caregivers reported this was a problem and an additional 31% said it was a major problem.

Figure 3: Work outcomes experienced by caregivers of adults with IDD



Due to caregiving responsibilities, caregivers reported turning down promotions (34%), receiving warnings about work performance (23%), losing job-related benefits (24%), or not moving out of state to pursue career opportunities due to the lack of Medicaid portability (30%).

Benefits offered by employers. Less than half of working caregivers reported that their employer offered paid time off in order to care for a family member (40%). 63% percent of the caregivers reported that their employer offered paid sick days. A substantial majority of caregivers (85%) thought that offering partially paid leaves of absence from work to meet caregiving responsibilities would be helpful or very helpful.

Summary and Discussion

The Family and Medical Leave Act of 1993 allows up to 12 weeks of unpaid, job-protected leave for family caregiving. According to the U.S. Department of Labor (2013), almost 60% of covered workers have used FMLA leave. However, the FMLA does not cover small employers with fewer than 50 people, and other stipulations such as hours worked and length of tenure often render part-time employees ineligible (Chen, 2016). As a result, only about 60% of U.S. workers are covered by the FMLA, and because leave under the FMLA is not paid, many low-wage workers are unable to take leave (U.S. Department of Labor, 2013).

To fill this gap, a growing number of states and businesses have created or are considering paid family and medical leave programs (Vasel, 2018). Typically, these programs provide partially paid leaves of absence for workers who are new caregivers or who need to address their own or a family member's serious medical condition. Even with this positive trend, only 15% of civilian workers have access to paid family leave (U.S. Department of Labor, 2017).

Workers and caregivers such as the caregivers in the *FINDS* survey consistently report that having paid leave would be beneficial (Menasce Horowitz et al., 2017). While some employers worry that paid family or sick leave policies will be harmful to business or job growth, many see significant benefits for their workers and bottom line (The Urban Institute, 2009; Small Business Majority and Center for American Progress, 2017). Studies show that paid leave policies are beneficial to employers because they reduce turnover rates, increase productivity, and increase employee loyalty and morale (Awuor & Arellano, 2011; Drum Major Institute for Public Policy, 2010; Economic Opportunity Institute, 2013). Analyses of California's paid family leave found that unpaid caregivers who were working were better able to balance work and care responsibilities (Saad-Lessler & Bahn, 2017). Paid leave also encouraged unemployed caregivers to join the labor force with a long-term increase in labor force participation of 14% (Saad-Lessler & Bahn, 2017).

Caregivers of adults with IDD report a number of negative economic outcomes. For example, on average, families that include a person with a disability have annual incomes 30 percent lower than families where no one has a disability (Grant et al., 2017). Gaps in our nation's system of LTSS and the shortage of direct support professionals hinder caregivers' ability to find support for their family member so that they can work. In *FINDS*, caregivers reported difficulties meeting work responsibilities

and taking care of their own health; more than half also reported that paying for care was a challenge.

The average age of the caregivers in this sample was 58 years. As caregivers age, the negative effects on their economic status as well as their own health will likely pose greater challenges in their retirement and for the on-going support of their family member with IDD. Caregivers are already a critical source of support for adults with IDD. Given the aging population and the shortage of qualified workers to provide LTSS, the role of family caregivers will become even more important. The potential cost to the LTSS system, should family caregivers be unable to provide care, would be significant. Paid leave has the potential to be an important tool to support caregivers by easing the negative economic effects of caregiving, and thereby, improving overall outcomes for caregivers and supporting their continued ability to provide care to their loved ones.

More about the *FINDS* survey

In 2017, the RTC/CL and The Arc conducted a national Internet survey that aimed to capture the experiences of family caregivers of people with IDD. Nearly 3,400 caregivers from every state, 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 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 data brief analyzes an income-matched subsample of 1,225 *FINDS* respondents that reflects the household incomes of the U.S. This subsample was chosen based on the proportion of households at each income level reported by the U.S. Census Bureau at factfinder.census.gov.

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