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Employment outcomes and paid leave for caregivers of children 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 parents of children with IDD and the need for paid leave policies. This brief examines a *FINDS* subsample of 388 caregivers of minor children with IDD, ages 0-17.

Background

The rate of parental employment has increased since 1967, leading to more dual-earner households (Fox et al., 2013). However, the amount of time spent on caring for minor children has not decreased, indicating that parents are dropping other activities such as housework or time for themselves, and find themselves stretched for time and multi-tasking (Bianchi, 2010; Fox et al., 2013). Parents of children with disabilities often have

extra demands on their time beyond that of parents of typically developing children. These demands can include coordination of support services, providing access to medical treatments, behavioral support, or providing assistance with daily activities that are not typical for a child of the same age without disabilities.

National surveys of caregivers of adults with disabilities or who are aging show that 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 (National Alliance for Caregiving, 2015). Findings from the National Survey of Children's Health show that parents of children with more complex needs report negative impacts on employment, such as reducing work hours or quitting work, more frequently than parents of children with less complex needs (Ouyang et al., 2015; Saunders et al., 2015). The *FINDS 2017* survey asked parents about their employment status, ability to take paid leave, and effects of caregiving on work and on caregiver outcomes such as self-reported levels of stress and health status.

Findings

Demographics. 364 (94%) of the 388 caregivers were parents, 3% were grandparents, and the rest had some other relationship to the child with IDD. For the purpose of this brief, all caregivers will be referred to as parents. Most parents (79%) reported caring for one child with IDD. 83% of parents reported providing more than 40 hours of care per week. Most of the parents in this sample were women (93%). 83% identified as white, 5% as Latino/a, 5% as mixed race, 4% as black, and 4% as other.

Caregiver health and stress. Only 25% of parents reported that their health was very good or excellent; most reported that it was good (39%) or fair (28%). Two-thirds of parents reported the caregiving responsibilities had made their health worse (63%) and that they were very or extremely stressed (66%). 77% reported that they had a problem finding time to care for their own health issues. Parents also reported that being able to pay for support for their child was somewhat of a problem (39%) or a major problem (50%).

Figure 1: Health Status Reported by Parents

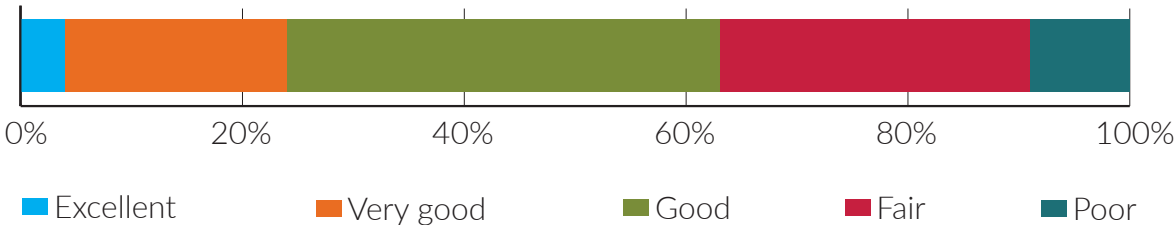
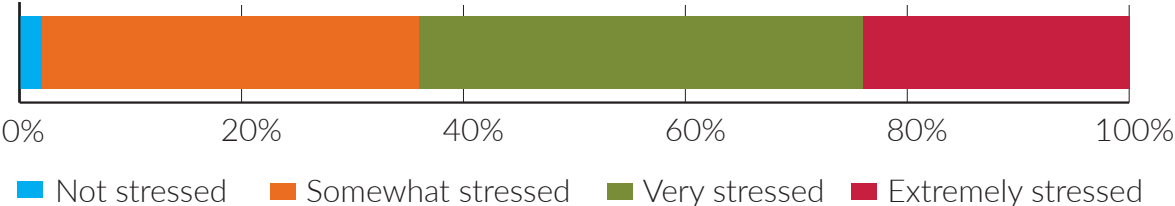


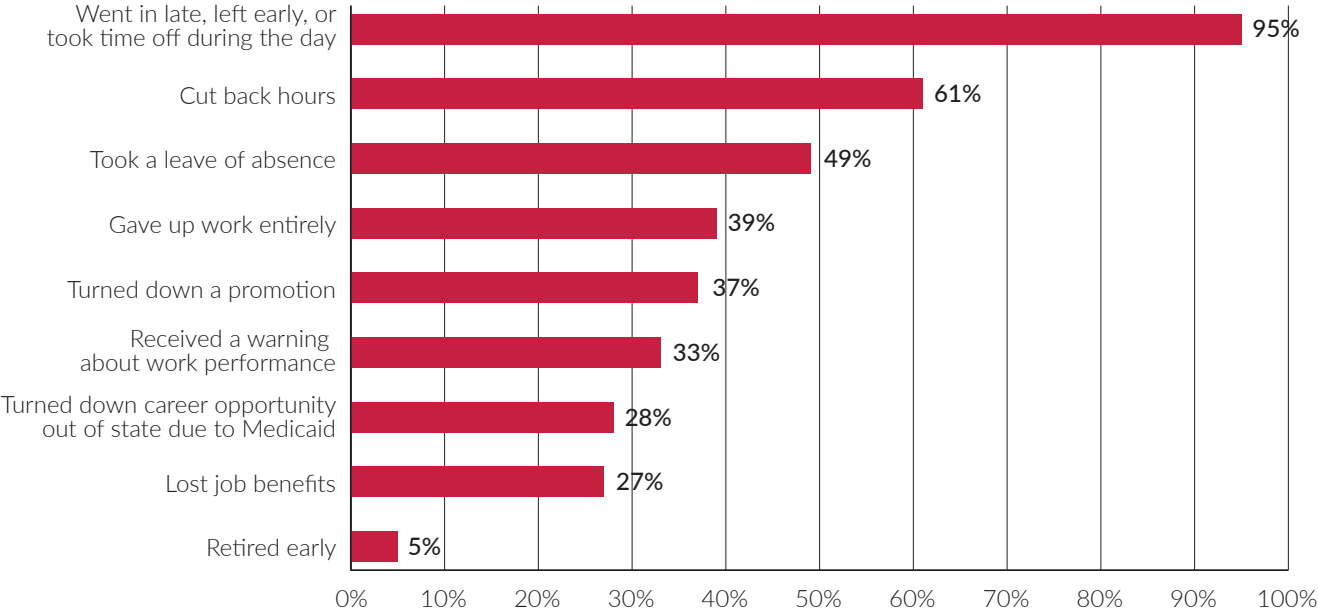
Figure 2: Stress Levels Reported by Parents



Employment and employment-related outcomes. Parents were asked if they had worked in the previous 12 months. Most of the parents reported being employed, either by someone else (60%) or self-employed (8%), working an average of 32 hours in addition to the supports they provided for their child with IDD. 76% of parents who worked agreed that their role as a caregiver interfered with work. 89% reported that adjusting their work schedules and meeting their work responsibilities was a problem. Nearly all parents (95%) reported that they had gone into work late, left early, or took time off during the day to meet their caregiving responsibilities. Nearly two-thirds of parents who were currently employed or who had been employed (61%) reported cutting back hours, half took a leave of absence (49%), and another 39% gave up work entirely. Compounding the challenges of meeting work and care responsibilities are the challenges of finding care while the parents are at work. 32% of parents reported this was a problem and an additional 49% said it was a major problem.

About one third of all caregivers reported turning down promotions (37%) or receiving warnings about work performance (33%). Slightly more than a fourth of all parents report losing job-related benefits (27%) or did not move out of state to pursue career opportunities due to the lack of Medicaid portability (28%).

Figure 3: Work outcomes experienced by parents of children with IDD related to caregiving responsibilities



Benefits offered by employers. Less than half of working parents reported that were able to take paid time off to care for their child (42%). 57% percent of the parents reported that their employer offered paid sick days. A substantial majority of parents (86%) thought that offering partially paid leaves of absence from work to meet caregiving responsibilities would be helpful or very helpful.

Summary and Discussion

All parents of children face challenges balancing work, child-rearing, and family responsibilities. However, parents of children with IDD often perform caregiving duties related to their child's disability beyond what is typical for child-rearing. Caring for children with IDD can have negative impacts on work, and ultimately the family's economic health. For example, on average, families that include a person with a disability – such as a minor child – have annual incomes 30 percent lower than families where no one has a disability (Grant, K. et al., 2017). Significant numbers of parents in this *FINDS* survey sample reported cutting back on hours or quitting work in order to meet the support needs of their child. These parents' challenges are compounded by the difficulty finding care for their children while they are at work, driven in part by the nationwide shortage of qualified direct support professionals (President's Committee on People with Intellectual and Developmental Disabilities, 2017).

The Family and Medical Leave Act of 1993 (FMLA) allows up to 12 weeks of unpaid, job-protected leave for family caregiving. According to the U.S. Department of Labor (2013), FMLA leave has been used by almost 60% of covered workers. However, the FMLA does not cover small employers with fewer than 50 workers, 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 parents or who need to address their own or a family member's serious medical condition.

Workers and caregivers such as the parents 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 program found that it supported unpaid caregivers who were working to better 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).

Parents raising children with IDD face economic challenges related to the care their child needs. Meeting these needs can lead to negative impacts on work and can cause parents increased stress and health concerns. Providing paid leave to parents to care for their children has the potential to improve the economic health of these families.

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 databrief analyzes an income-matched subsample of 1,225 *FINDS* respondents to better reflect household incomes of the U.S. This subsample was chosen based on the proportion of households at each income level reported by the United States Census Bureau at factfinder.census.gov.

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