

**POLICYLAB**

RESEARCH AT A GLANCE | SPRING 2023

A SYNOPSIS OF EMERGING POLICYLAB RESEARCH

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# THE BALANCE OF EMPLOYMENT AND PARENTING A CHILD WITH MEDICAL COMPLEXITY

**WHAT IS THE PROBLEM:**

Children with medical complexity are a subgroup of children with special health care needs whose conditions typically require ongoing care from multiple providers.

The complexity of their conditions places these children at risk for recurrent hospitalizations, often with admissions to the hospital following emergency department visits and longer lengths of stay than other children.<sup>1,2</sup>

Parents of children with medical complexity have reported challenges with maintaining employment due to the demands of caregiving. These challenges include the need to take unplanned leave from work, reduce their hours of work or leave the workforce entirely.<sup>3</sup> As a result, parents of children with medical complexity describe negative impacts on their income, savings, and job advancement, as well as their own mental health.<sup>4-6</sup>

The Family and Medical Leave Act (FMLA) is the primary federal U.S. policy that provides employment protections for individuals with caregiving responsibilities, covering up to 12 weeks of job protection without pay while an employee cares for themselves, a new child or a family member with a serious health condition.<sup>7</sup> While several states have enacted their own paid family and medical leave policies, workers in the vast majority of states only have access to the unpaid federal policy, which has eligibility criteria that severely and disparately limits access to leave.

While FMLA may allow some parents to balance the competing demands of employment and caregiving, how its protections are accessed and perceptions of the policy’s value among parents of children with medical complexity—given their unique caregiving responsibilities—have not been well articulated.

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**WHAT WE ASKED:**

What are the caregiving obligations of parents of children with medical complexity?

How effectively does the Family and Medical Leave Act (FMLA) support their dual role as caregiver and employee?

How does this dual role affect caregivers’ employment stability and economic security?

**WHAT WE DID:**

We recruited caregivers of children enrolled in a Philadelphia pediatric primary care practice’s intensive care management program designed to support the families of children with complex chronic conditions who participate in a Medicaid managed care plan.

We then conducted semi-structured interviews with 16 parents of children with medical complexity. Interview questions incorporated a variety of topics related to support networks, employment status, medical needs of their children, financial strain caring for their children, and FMLA knowledge and experiences.

**WHAT WE FOUND:**

**Caregivers expressed:**



**Changes to work status**

*Unpredictable time commitments dictated by their child’s health status and medical care made it difficult to maintain the regular schedule that employers generally require.*



**Inconsistent and intermittent access to FMLA benefits**

*Those who said they were ineligible for FMLA were not always sure why, citing possible reasons including part-time hours and having used up the maximum allotted leave. Even parents who did qualify for FMLA were left vulnerable, most often sharing about the financial hardship of leave without pay.*



**Variable workplace supports**

*Work environments, such as the relationship with a supervisor, impacted employment experience and ability to take time off for their child’s medical needs. Some parents described being offered informal leave agreements, either as an alternative to or when they were not eligible for FMLA.*



**Prohibited professional growth**

*Presented with career advancement opportunities, parents were wary of additional time commitments and new responsibilities, and some described opting out of promotions.*



**Financial hardship**

*The combined uncovered health care costs and associated costs of unpaid time off and loss of income—due to employment changes—resulted in financial hardship. Seemingly small expenses, like the cost of parking or eating at the cafeteria during a long hospital stay, amounted to significant costs. Home health aides paid for by Medicaid and food assistance from the Supplemental Nutrition Assistance Program were important sources of stability.*



**Emotional and physical strain**

*Participants’ experiences managing work and their child’s medical needs were emotionally and physically taxing. On top of juggling their job responsibilities and their child’s medical needs, parents described difficult realities such as selling the family car to make ends meet or relocating to be near medical services.*

**WHAT IT MEANS:**



## STUDY METHODS

We recruited caregivers of children enrolled in a Philadelphia primary care practice's intensive care management program designed to support the families of children with complex chronic conditions who were enrolled in a Medicaid managed care plan. Eligible patients had an upcoming appointment at the time of recruitment and met one of the following criteria: a)  $\geq 2$  complex chronic conditions, or b) 1 complex chronic condition and  $\geq 2$  inpatient admissions within the previous 12 months.

Members of the study team conducted semi-structured, individual interviews between November 2018 and August 2019. Questions covered family context and personal support networks; work status of heads of household; the relationship between their child's medical needs and current or past employment status of the heads of household; experience of financial hardship related to caregiving; and caregiver knowledge of and experiences with FMLA.

We took an integrated approach to develop our codebook and direct our thematic analysis, reading through early transcripts as a team to identify themes emerging from the data, as well as integrating a priori codes informed by our research questions.

## RELATED POLICYLAB WORK

Montoya-Williams D, Passarella M, Lorch SA. The impact of paid family leave in the United States on birth outcomes and mortality in the first year of life. *Health Services Research*. 2020;55(S2):807–814. [doi.org/10.1111/1475-6773.13288](https://doi.org/10.1111/1475-6773.13288)

## PUBLICATION

Kellom KS, Wilson-Hall CL, Strane D, Wu K, Matone M. Employment and leave while parenting children with medical complexity. *Families, Systems, & Health*. 2023. [doi.org/10.1037/fsh0000802](https://doi.org/10.1037/fsh0000802)

## BIBLIOGRAPHY

- Berry JG, Hall DE, Kuo DZ, Cohen E, Agrawal R, Feudtner C, Hall M, Kueser J, Kaplan W, Neff J. Hospital utilization and characteristics of patients experiencing recurrent readmissions within children's hospitals. *JAMA*. 2011;305(7):682–690. [doi.org/10.1001/jama.2011.122](https://doi.org/10.1001/jama.2011.122)
- Coller RJ, Rodean J, Linares DE, Chung PJ, Pulcini C, Hall M, Alpern E, Mosquera R, Casto E, Berry JG. Variation in hospitalization rates following emergency department visits in children with medical complexity. *The Journal of Pediatrics*. 2019;214:113–120. [doi.org/10.1016/j.jpeds.2019.07.034](https://doi.org/10.1016/j.jpeds.2019.07.034)
- Foster CC, Chorniy A, Kwon S, Kan K, Heard-Garris N, Davis MM. Children with special health care needs and forgone family employment. *Pediatrics*. 2021;148(3):e2020035378. [doi.org/10.1542/peds.2020-035378](https://doi.org/10.1542/peds.2020-035378)
- Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges of more-complex children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*. 2011;165(11):1020–1026. [doi.org/10.1001/archpediatrics.2011.172](https://doi.org/10.1001/archpediatrics.2011.172)
- Schuster MA, Chung PJ, Elliott MN, Garfield CF, Vestal KD, Klein DJ. Perceived effects of leave from work and the role of paid leave among parents of children with special health care needs. *American Journal of Public Health*. 2019;99(4):698–705. [doi.org/10.2105/AJPH.2008.138313](https://doi.org/10.2105/AJPH.2008.138313)
- Thomson J, Shah SS, Simmons JM, Sauers HS, Brunswick S, Hall D, Kahn RS, Beck AF. (2016). Financial and social hardships in families of children with medical complexity. *The Journal of Pediatrics*. 2016;172:187–193. [doi.org/10.1016/j.jpeds.2016.01.049](https://doi.org/10.1016/j.jpeds.2016.01.049)
- U.S. Department of Labor. Family and medical leave (FMLA). <https://www.dol.gov/general/topic/benefits-leave/fmla>



The mission of PolicyLab at Children's Hospital of Philadelphia (CHOP) is to achieve optimal child health and well-being by informing program and policy changes through interdisciplinary research. PolicyLab is a Center of Emphasis within the Children's Hospital of Philadelphia Research Institute, one of the largest pediatric research institutes in the country.

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