Juggling Demands of Employment & Caring for a Child with Medical Complexity: Opportunities to Improve Public Policy

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Parents of children with medical complexity face particular challenges balancing caring for their children, maintaining employment and earning income that their family needs. That's because children with medical complexity require frequent medical appointments, a great deal of care coordination, are at an increased risk of recurrent hospitalizations and can require lengthy hospital stays. Parents of these children are in need of public policies that support their competing priorities of stable income and the ability to care for their child, as a matter of equity and a critical component of ?a caregiving agenda.

Parents of children with medical complexity could be better supported through a number of policy changes, including models of paid family caregiving that are gaining momentum in states, payment policy that supports improved care coordination or investments in the home health care workforce. Widespread adoption of any of these policy shifts could transform the landscape. In this post, however, we'll explore caregivers' current ability to take leave from their job without these supports and specifically without access to caregiving leave, which is the focus of a new PolicyLab qualitative research study and *Research at a Glance* resource.

Limitations of Caregiving Leave Under the Family Medical Leave Act (FMLA)

Many families with children with medical complexity have no access to caregiving leave from their job. Those who do are dependent on a patchwork of options, including paid leave offered through some employers, state paid leave policies (13 have enacted paid family leave laws as of early 2023) or unpaid leave with job protection through the Family Medical Leave Act (FMLA). There are notable racial and ethnic as well as income-based disparities in access to these options, and the United States remains the only high-income country without a

comprehensive family and medical paid leave policy.

FMLA, which recently marked its 30th anniversary, allows workers to take up to 12 weeks of unpaid leave for specific family and medical reasons and ensures that their job will still be there when they return. Passage of the FMLA was a major step forward, but with its stringent eligibility requirements, there are many individuals who do not qualify for it. Here in Pennsylvania, where there is no state-level paid leave policy, FMLA is only accessible to about 40% of workers. Even among those who do qualify for FMLA, many cannot afford to take unpaid leave from their job.

New Research Outlines Employment Challenges Parents Face While Caring for a Child with Medical Complexity

New PolicyLab research looks at the needs of parents of a child with medical complexity and examines the availability and appropriateness of FMLA in supporting these individuals as caregivers *AND* employees. The study team interviewed 16 parents who are part of an intensive care management program in Philadelphia to unpack the ways in which the dual role of serving as a caregiver and employee affected caregivers' employment stability and economic security. All of those interviewed were mothers who were Medicaid beneficiaries and over half were single parents.

Parents described that caring for their child required ongoing and unpredictable time commitments that conflicted with job duties or schedules. For some parents, the 12 weeks of job protection offered by FMLA was not enough. Some of the parents in the study had access to employer-specific leave policies, but these policies were inconsistent and failed to offer the formal protections of FMLA. Parents discussed wanting to work and excel in their professional lives and expressed wanting a job that would better align with the responsibilities of their non-negotiable caregiving role. Interestingly, some parents described how the gig economy supplied opportunities for extra income with more flexible hours.

Related to FMLA eligibility specifically, the study found:

- Prioritizing caregiving responsibilities led to frequent employment changes that negatively impacted financial health, personal well-being and eligibility for FMLA.
- Many parents said that they could not access FMLA due to their part-time employment status, insufficient tenure at their job or the unaffordability of unpaid leave.
- The FMLA requirement that an employee works a full year before becoming eligible left some parents feeling trapped in their job to maintain access to FMLA benefits.

The financial impact of caregiving can be severe—nearly half?of family caregivers report losing income to take time off to fulfill responsibilities at home. Providing greater support to family caregivers is also vital to ensuring racial and gender equity. Among families in which unpaid care is provided to one or more family members, Black and Latino families?are more likely?than White and Asian American families to have a lower household income. Additionally, almost?1 in 7 women?provide care to family members or friends.

Policy Opportunities to Better Support Caregivers

Our PolicyLab study illustrates some of the limitations of FMLA for caregivers of children with medical complexity. While FMLA provides important short-term job protection for eligible employees, the policy offers insufficient flexibility for the long-term and unpredictable medical needs of children with medical complexity. The findings highlight the importance of flexible paid family and medical leave (among other things) for the health and well-being of families, particularly for those in which a family member needs life-long care.

In addition to the benefits to families, it is in the country's economic interest to support its workforce. Paid leave policies poll well across the political spectrum, and there have been welcome efforts at the federal level and in Pennsylvania for much-needed reforms. That said, as mentioned earlier, there are a number of policy

opportunities to better support caregivers of children with medical complexity, all of which would have a greater impact if implemented together. Families need policymakers to take a holistic approach that supports them as both caregivers and members of the workforce in order to allow them to thrive.

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