Disability Perspectives on Leave: A Qualitative Inquiry on the Leave-Taking Experiences of Workers Affected by Disabilities & Serious Health Conditions

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Introduction

People with disabilities and serious health conditions and their caregivers experience high levels of poverty and unemployment. Policies that support leave from work to address a health condition or provide care for a family member bolster the economic security and health of workers, improve employee morale, and reduce turnover. Researchers conducted semi-structured phone interviews with 90 workers in three states with PFML programs: California, New Jersey, and North Carolina. Interviews were transcribed, coded using ATLAS.ti 8, and analyzed with the Framework and Grounded Theory approaches.

The Family and Medical Leave Act (FMLA) is the only federal leave protection for workers. It offers 12 weeks of unpaid, job-protected leave. However, a growing number of workers have access to paid family and medical leave (PFML) through state-level programs.

Most research about paid leave focuses on pregnant workers and new parents. It is vital that the perspectives of workers affected by disabilities and serious health conditions are included in policy conversations about paid leave to ensure that paid leave programs work for everyone.

With funding from The Arc of the United States, the National Center for Children in Poverty conducted a qualitative study of the needs for paid leave among workers with disabilities and serious health conditions and those who care for them.

Research Questions

1. What are the leave-taking experiences of workers affected by disabilities and serious health conditions and working caretakers in the U.S.?
2. What are the barriers to leave-taking among this population?
3. How can key stakeholders (Policymakers, program administrators, employers, and advocacy organizations) better support the leave-taking experiences of this population?

Methods

Researchers conducted semi-structured phone interviews with 90 workers in three states with PFML programs: California, New Jersey, and North Carolina. Interviews were transcribed, coded using ATLAS.ti 8, and analyzed with the Framework and Grounded Theory approaches.

Findings: Barriers to Leave Programs

Lack of awareness and information about the programs

“Painful to know that I could take leave to rest and also get paid, I would’ve done that. I had to instead work double to make up for what had happened rather than being able to rest and then come back restored and replenished.” - North Carolina worker with a physical condition

Fear of job loss

“I remember reading about FMLA when I was trying to take this leave, and I thought that it didn’t cover siblings – that it’s just for parents and children and spouses...” - California caregiver, providing support for her younger brother with an intellectual and/or developmental disability

Unclear family leave definition

“I need to be paid 100%, not 60% of wages in order to pay my bills.” - New Jersey caregiver

Inadequate coverage for self-employed and public workers

“Being self-employed was really the only option at this point because, my son, still needs a significant amount of support.” - New York caregiver with a disability and serious health condition

Stigma of disability

“The stigma is that you’re lazy, you can’t keep up, you can’t sustain, so why would the company give you time off?” - north Carolina worker with a serious health condition

Narrow or unclear covered conditions

“Because of how narrow the definitions are it makes me nervous to take this...” - North Carolina caregiver, providing support for her younger brother with an intellectual and/or developmental disability

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Recommendations

Create a comprehensive, inclusive, national paid leave program.

Provide job protection for paid leave programs.

Include anti-retaliatory provisions.

Ensure sufficient wage replacement and maximum benefits.

Provide an inclusive definition of covered family.

Ensure that application processes are as simple as possible for all parties.

Cover self-employed and public employees in paid leave programs.

Allow for hourly leave under all paid leave programs.

Provide an adequate amount of leave time.

Ensure that covered reasons for taking paid leave reflect the needs of people with disabilities and their families.

Invest in outreach and education campaigns.

Ensure adequate resources for paid leave insurance programs.

Inform all employees regularly about available leave programs.

Implement a documented process for leave-taking.

Allow for flexible use of employer-provided time.

Allow for flexible work schedules and remote working options, when possible.

Foster an inclusive work environment.

Conduct outreach to healthcare providers.

Use online communities for outreach and education.

Coordinate with service and advocacy organizations.

Conduct outreach to health insurance providers, including managed care organizations.

Study Population

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Number of people living with conditions in category

Number of people who provided care for someone with condition in category

Intelectual and/or Developmental Disability (IDD)

6

55

Neurological condition, other than IDD

11

16

Physical condition, other than IDD or neurological condition

28

19

Mental illness, other than memory issues

15

15

Memory issues

0

8

Visual impairments

Less than 5

Less than 5

Other or unclear

0

13

Technical note: All estimates are weighted. *Exact numbers are not reported to ensure confidentiality.