



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.¹ 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.^{2,3,4,6}

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 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?

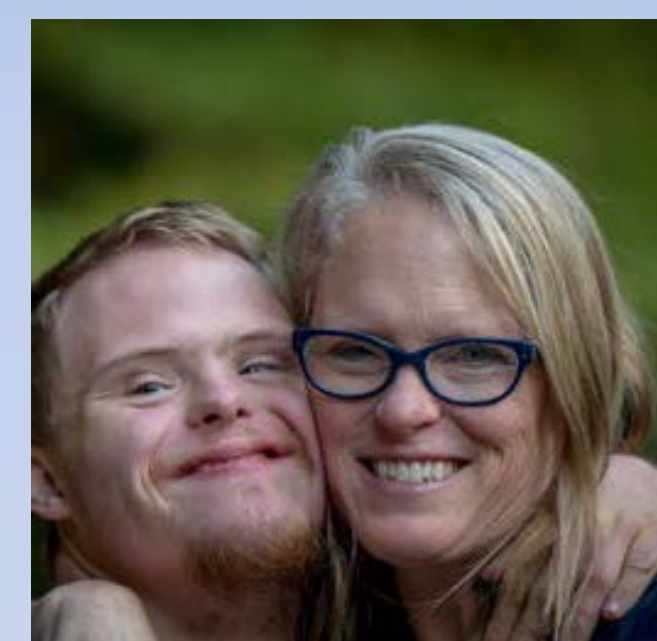
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Methods

Researchers conducted semi-structured phone interviews with 90 workers in three states with PFML programs: California, New Jersey, and New York, and one state without a PFML program: North Carolina. Interviews were transcribed, coded using ATLAS.ti 8, and analyzed with the Framework and Grounded Theory approaches.

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
Intellectual 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

*Exact numbers are not reported to ensure confidentiality.

Findings: Barriers to Leave Programs

Lack of awareness and information about the programs

"Had I known that I could take leave to reset 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 caregiver with a disability and serious health condition

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

Fear of job loss

"I'm always afraid they'll let me go...I can't take those two days off, because I worry about losing my job, because that's my full-time job. I get the health insurance benefits for the whole family, so it makes me nervous to take off." - New Jersey caregiver

Government bureaucracy/lack of transparency

"When I applied for PFL, they took almost a month to approve it, and, despite turning in the paperwork the same day...I wasn't getting consistent payments. I'd get a large payment and then go through a really long break and get another larger payment...you can't call any number to speak to a human. It's just voice prompts that lead you in a billion circles." - California caregiver who tried to take PFL to care for husband's injury

Narrow or unclear covered reasons for leave

"It's very hard to show that the needs of a person with a developmental disability and all of the therapies and appointments, are a medical condition." - New York caregiver with two minor children with disabilities

Stigma of disability

"The stigma is that you're lazy, you can't keep up, you can't sustain, so why would the company keep you on?" - North Carolina worker with a serious health condition



Unclear family definition

"I remember reading about FMLA when I was trying to take this leave, and I read that it doesn't cover siblings - that it's just for parents and children and spouses." - California caregiver, providing support for her younger brother with autism

Inadequate wage replacement

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

Recommendations

For Policymakers	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.
For Employers	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.
For Advocates	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.

