

DISABILITY PERSPECTIVES ON PAID LEAVE

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A Qualitative Analysis of Leave-taking Among Workers Affected by Disabilities or Serious Health Conditions

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Overview

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- **Sample Characteristics**
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Types of Leave

- **Medical leave**
 - To address one's own illness, injury, or health condition
- **Parental leave**
 - To bond with a new child (aka "bonding leave")
- **Family leave**
 - Parental leave + caregiving leave

The federal Family and Medical Leave Act (FMLA) covers all of the above, providing 12 weeks of unpaid, job-protected leave in a year.

Some states have paid family and medical leave programs (PFML) which cover all of the above.

Research Aims

- **Population of interest:**
 - **Workers with disabilities**
 - **Workers with serious health conditions**
 - **Workers who provide support for someone with a disability or serious health condition.**
- **To identify:**
 - **Leave-taking patterns**
 - **Barriers to leave taking**
 - **Ways in which key stakeholders can better support leave-taking needs**

Methods

- **Semi-structured, one-on-one telephone interviews**
- **Participants from states representing different policy contexts: CA, NJ, NY, and NC**
 - **CA and NJ have had PFML programs since 2002 and 2009 respectively**
 - **NY only began offering family leave benefits in 2018**
 - **NC does not have a paid leave program**
- **Question focus**
 - **Experiences managing work and health needs and/or support to others.**
 - **Leave-taking needs and experiences**
 - **Trusted sources of information.**

Sample Characteristics

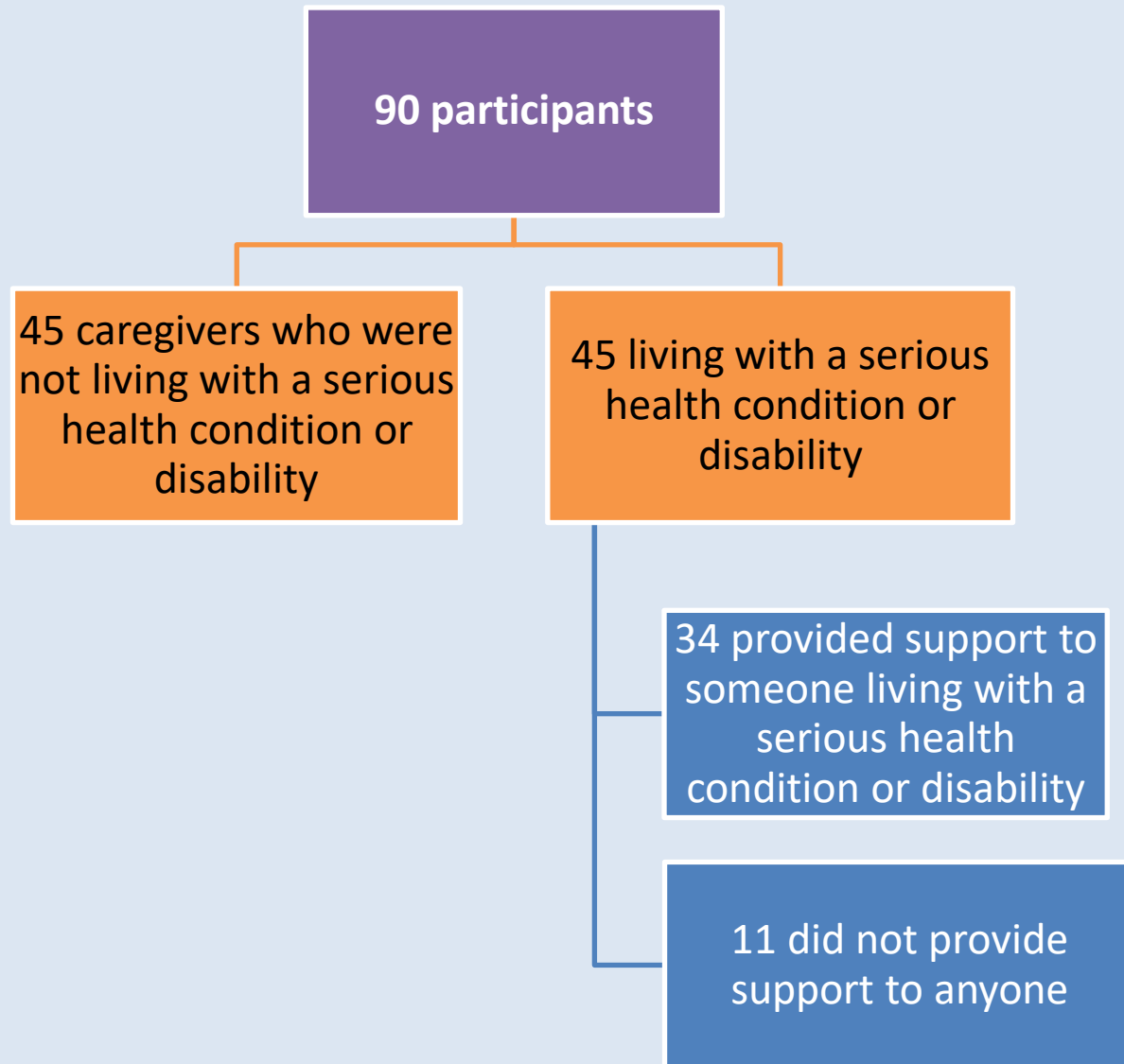
90 participants met following criteria:

Worked in the past two years in one of the four states

Identified as:

- someone with a disability or serious health condition **and/or**
- provided care to a loved one with a disability or serious health condition within the past two years

Sample Characteristics



Sample Characteristics

Distribution of disabilities or health conditions by category and by own condition or caregiver

	# interviewees with conditions in category	# interviewees 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 of participants are not reported when less than five to ensure participant confidentiality.*

Sample Characteristics

Income as a percentage of state median household income

% of state median income for their household size	Number of participants	NC	NY	NJ	CA	% of total participants
<50%	20	3.33%	11.11%	4.44%	3.33%	22.22%
<100%	51	15.56%	17.78%	16.67%	6.67%	56.67%
<150%	77	22.22%	23.33%	23.33%	16.67%	85.56%
<200%	85	26.67%	24.44%	25.56%	17.78%	94.44%
>200%	4	0.00%	2.22%	0.00%	2.22%	4.44%
not available	1	0.00%	0.00%	0.00%	1.11%	1.11%
Total	90	26.67%	26.67%	25.56%	21.11%	100.00%

State median income levels are based on American Community Survey 2012-2016, 5-year estimates, Table B19019, see below table for details.

Key Findings

Workers take leave for diverse and often disability-related reasons.

Workers want to maximize their time at work and benefit when they use paid leave in conjunction with other employment benefits.

Workers value the Family and Medical Leave Act (FMLA) and other leave options.

There are multiple barriers and gaps that limit workers' access to leave, including stigma against disabilities and fear of job loss.

Multiple Barriers and Gaps Limit Workers' Access to Leave

Fear of job loss (including lack of employer support and stigma against disabilities)

"I'm always afraid they'll let me go. I can't take even 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

Inadequate wage replacement

"I need to be paid 100% wages, not 60% 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 I can't meet the criteria of a regular job. My son is high-school age and still needs a significant amount of support. Being able to show up on time and not have to call off work or be distracted because I can't find enough support to meet his needs, that was a major factor in [becoming self-employed]."

New York caregiver with a disability and serious health condition

Low awareness and understanding of the program

“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

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 things that go along with it, all of the therapies and appointments, are a medical condition.”

New York caregiver with two minor children with disabilities

Bureaucracy that resulted in confusing information and a complex process

“The rules seem to be always changing. There’s different programs and they all sort of have similar names but they’re different. That’s complicated. Figuring out what’s federal and what’s state gets confusing, and if you don’t have a good person where you’re working whom you trust to help you through it, I’m not really sure how people do it.”

New York worker with disability

Narrow definition of family

“Well, I remember reading about FMLA when I was trying to take this leave, and that’s when 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

Recommendations

For policymakers

Create a comprehensive, inclusive, national paid leave program. 1

Provide job protection for paid leave programs. 2

Include anti-retaliatory provisions. 3

Ensure sufficient wage replacement and maximum benefits. 4

Provide an inclusive definition of covered family. 5

Ensure that application processes are as simple as possible for all parties. 6

Cover self-employed and public employees in paid leave programs. 7

Allow for hourly leave under all paid leave programs. 8

Provide an adequate amount of leave time. 9

Ensure that covered reasons for taking paid leave reflect the needs of people with disabilities and their families. 10

Invest in outreach and education campaigns. 11

Ensure adequate resources for paid leave insurance programs. 12

Recommendations

For Employers

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.

For Advocates

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.

Why is it important to incorporate the needs of the disability community into paid family and medical leave policy?

Medicaid and other federal or state-run public health insurance programs often include means-tested eligibility requirements.

Most employer and non-group/marketplace plans require families to pay a portion of health insurance costs.

It can be advantageous for workers in families that include people with disabilities who incur very high healthcare costs to lower their income in order to qualify for Medicaid. This can result in quitting a job or switching to a lower-paying job.



Why is it important to incorporate the needs of the disability community into paid family and medical leave policy? (continued)

Compared to people working higher-paying jobs, people working lower-paying jobs often:

- Have less job stability/security
- Are less likely to work for employers that offer paid family and medical leave
- Work jobs whose wages barely cover or do not fully cover the cost of basic necessities.

Because of the above factors, for the population of low-income workers in families that include individuals with disabilities, any loss of income resulting from leave from work could have a significant effect on family finances.

Paid family and medical leave helps reduce the impact of lost income for this population resulting from taking leave from work.

Case Study: “Isabel”

- Lives in North Carolina
- Caretaker for her husband, who has a neurological disorder that prevents him from working full-time.
- Her husband’s condition results required significant medical attention at initial diagnosis, requires ongoing care, and requires care for periodic, unpredictable medical crises.
- Has cancer herself
- Currently has a full-time job at a nonprofit performing administrative work
- Previous employer, who paid her over twice as much as her current salary, pressured her to leave because he was unwilling to accommodate her requests for a flexible work schedule.

Wait time for Medicaid on Social Security Disability

“You have to be disabled a year before you can get SSD, and he had no problem with that [because he had been disabled for over a year]. But then you have to be on social security for two years before you can get Medicare.”
- “Isabel”. Also, ssa.gov.

- Her husband is medically qualified for enrolling early in Social Security Disability Insurance.
- To attain coverage during this time, SSA.gov suggests that SSDI beneficiaries may be eligible for coverage through a former employer, but in Isabel’s case, neither her employer nor her husband’s provided health insurance to cover him after he left his job.

Quitting her job

“Isabel”: I had to stay out of work to keep him on Medicaid until he qualified for Medicare.

Q: Did your income influence his eligibility as well?”

“Isabel”: Yeah, that's why I couldn't work. He wouldn't have had access to medical care.

For a family of 2, North Carolina’s Medicaid eligibility requirements for the state’s Medicaid for Aged, Blind and Disabled category currently include:

- An income limit is \$1,410/month, or \$16,920/year
- An asset limit of \$3,000.

Medicare Expenses

“Then I went back to work. At first I was paying \$800, and then it went to \$890, then \$965. I was paying \$1,000 a month for a Medicare supplement for him.”

- “Isabel”

- Medicare Part A (hospital coverage) usually requires no premium payments on the part of beneficiaries.
- Medicare Part B (covering preventive care and medically necessary services and supplies) costs:
 - A premium of \$130/mo. on average, coinsurance, and deductibles.
 - According to the U.S. Centers for Medicare & Medicaid Services, people typically pay 20% in coinsurance of the Medicare-approved amount for most doctor services, outpatient therapy, and durable medical equipment.
- To help cover deductible and coinsurance costs, many people purchase Medicare Supplement (Medigap) plans.
- Medigap plans per ZIP available at <https://www.medicare.gov/find-a-plan/questions/medigap-home.aspx>.

Coverage through North Carolina's Medicaid buy-in program

“Then I found out they had Medicaid for the working disabled, which has different qualifying numbers, so he can get that, and he’s been working almost three years.”

-“Isabel”

NC Health Coverage for Workers with Disabilities Act (a.k.a. Medicaid Buy-In):

- Passed 2006, fully implemented in 2013 by injunction following lawsuit.
- Provides Medicaid coverage for workers with disabilities ages 16-64.
- Unearned income (SSDI, Veteran’s benefits, alimony, child support, annuities, in-kind support, etc.), cannot exceed 150% FPL
- Workers with disabilities whose countable incomes (including income from co-habiting spouses) are above 150% of FPL must pay an annual enrollment fee.
- Workers with disabilities with countable incomes exceeding 200% of FPL must pay an enrollment fee and a monthly premium, based on a sliding scale up to the average cost of Medicaid claims (currently \$472/month).
- Currently has an asset limit of \$25,284

Employer Flexibility

“They’ve always been very flexible and supportive.”
- “Isabel”, regarding her current work situation

Without federal or statewide paid family and medical leave programs, workers with disabilities or working caregivers of people with disabilities are at the mercy of their employers for necessary time away from work, flexible schedules, etc.



Read the full report at

<https://www.thearc.org/paidleavestudy>

For more resources visit:

<https://www.thearc.org/paidleave>

<http://www.nccp.org>

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