

Disability Perspectives on Paid Leave

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

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Most people with disabilities or serious health conditions are [eager to work](#) to support themselves and their families, and to contribute meaningfully to society. Similarly, workers who provide unpaid care for loved ones with disabilities or serious health conditions typically [value their roles](#) as workers as well as caregivers. The successful workforce participation of people who have disabilities or of people who provide care often requires access to supports, accommodations, and protection against discrimination. Paid family and medical leave policies can provide vital support toward maintaining employment by allowing workers to take time away from work to address health needs.

Paid leave allows workers to take fully- or partially-paid time away from their jobs to address their own or a family member's serious health condition, or to bond with a new baby or newly adopted child. Without paid leave or when policies are inadequate, workers all too often face harsh and likely harmful choices – between a paycheck, or health and family.

Traditionally only offered by employers, an increasing number of state governments are creating their own paid leave insurance programs and policymakers are considering legislation to offer paid leave at the national level. While recent policy debates on paid leave have often centered on parents of newborns, leave policies must also meet the needs of workers with disabilities or serious health conditions, and caregivers. Roughly [one in five Americans](#) currently live with a disability, and roughly [one in four](#) households include a child, adult, or senior with a disability. Inclusive paid leave policies will not only benefit people with disabilities and their families but will also foster programs that are effective for all workers.

Groundbreaking Research Explores Disability Perspectives on Paid Leave

To date, little research exists on the experiences and perspectives of people with disabilities and their families to help inform development of disability-inclusive paid leave policies, at the state or national levels. To address this gap, the National Center for Children in Poverty (NCCP) at Columbia University, in collaboration with The Arc of the United States (The Arc), conducted a [groundbreaking qualitative study](#), interviewing 90 workers with disabilities and working caregivers in California, New Jersey, New York, and North Carolina.

Findings

Workers take leave for diverse and often disability-specific reasons. Study participants often reported providing primary support for multiple people, and many also identified as having a disability, a serious health condition, or both. Study participants took leave both for their own health needs and to provide support to a family member with a disability or serious health condition. While some participants took leave for long periods of time, many took leave for shorter periods of time or intermittently – even when the underlying need for leave was long-term. For example, parents of children with disabilities reported taking leave to attend a school meeting for their child's Individualized Education Plan. Participants also experienced a need for leave to address both predictable and unpredictable needs.

Workers want to maximize their time at work and benefit when they use paid leave in conjunction with other employment benefits. Study participants valued being able to use formal and informal arrangements with their employers to work flexible hours or from home. Many preferred to use fully-paid employer-provided paid time off when possible, and used partially-paid state leave insurance programs as a last resort. Many also used or expressed a desire to use hourly intermittent leave in order to minimize time away from work.

Workers value the Family and Medical Leave Act (FMLA) and other leave options. Many study participants used the FMLA and valued it for the flexibility it afforded them for managing health needs and work. Study participants expressed a desire for more understanding and support in the workplace, and those who experienced such support expressed loyalty

and gratefulness for their employers. Study participants who were aware of the state paid leave programs reported that they were glad such programs were available to them but desired a more efficient process for receiving benefits.

Multiple barriers and gaps limit workers’ access to leave. Among the people interviewed, barriers to accessing leave included:

- Low awareness and understanding of the program;
- Inadequate wage replacement;
- Narrow definition of family;
- Inadequate coverage for self-employed and public workers;
- Narrow or unclear covered reasons for leave;
- Bureaucracy that resulted in confusing information and a complex process; and
- Fear of job loss (including lack of employer support and stigma against disabilities).

Recommendations

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.
	Invest in outreach and education campaigns.
	Ensure adequate resources for paid leave insurance programs.
	Recommendations for employers
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.	
Recommendations for advocates	Conduct outreach to health care providers about leave programs.
	Use online communities for outreach and education.
	Coordinate with service and advocacy organizations.
	Conduct outreach to health insurance providers, including managed care organizations.

“ [Policymakers’] best resource is disabled people ourselves. Don’t tell us what we need. Come and ask us. The people closest to the problem are also closest to the solution. We just need the resources to make ourselves heard. ”

– North Carolina worker with a disability and serious health condition