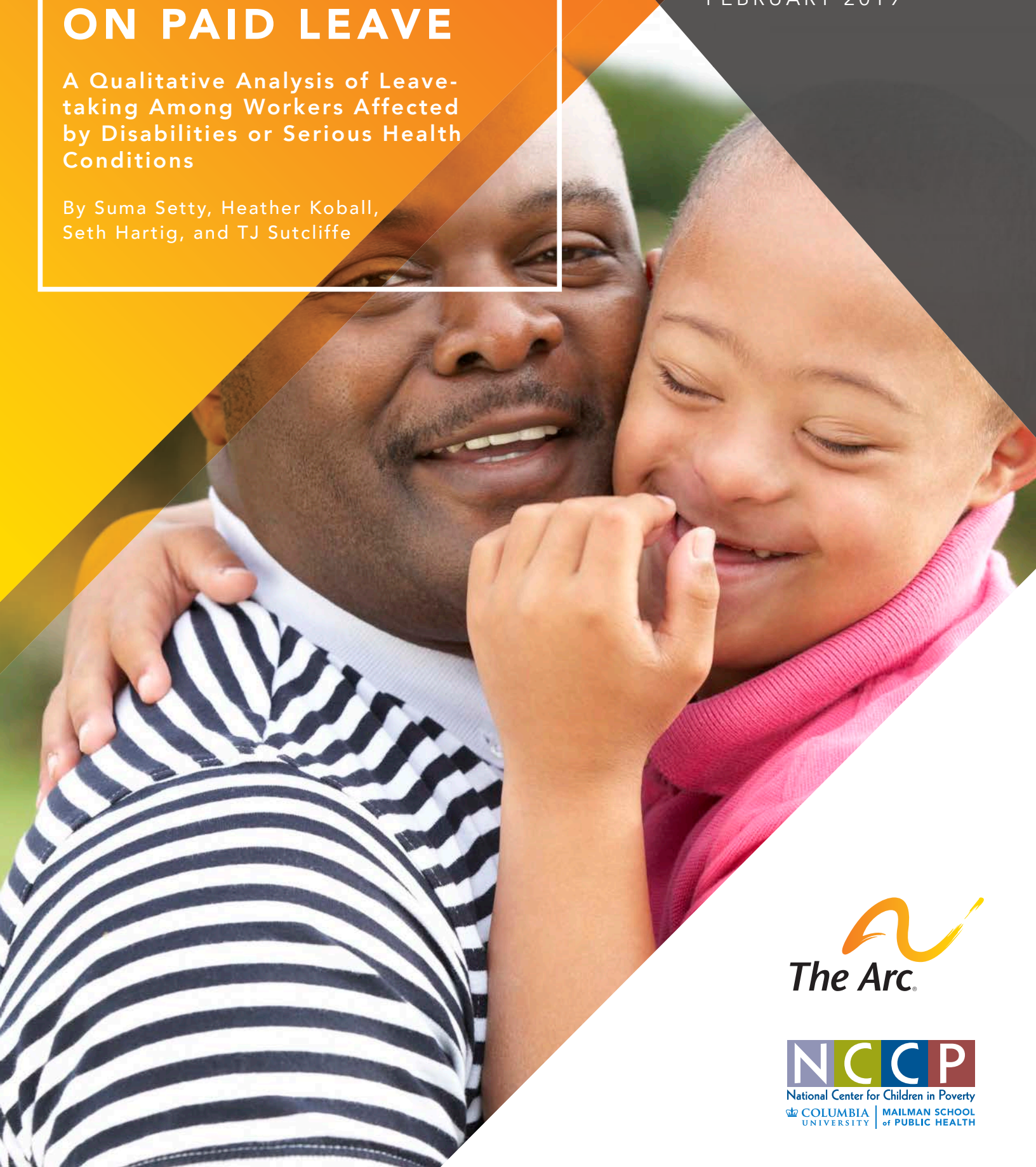


DISABILITY PERSPECTIVES ON PAID LEAVE

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

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The Arc

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EXECUTIVE SUMMARY

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 also value both their professional responsibilities as workers as well as their responsibilities 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, traditionally only offered by employers but more recently offered by an increasing number of state governments and debated on a national level, can provide additional and 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. With high-quality paid leave policies, workers can take time off to secure necessary medical care and supports for themselves or a family member, while still being

able to pay for basic expenses. Effective paid family and medical leave policy can support worker health, strengthen families, and promote household economic security.

While recent policy debates on paid leave have often centered on new parents, leave policies must also meet the needs of workers with disabilities, workers with serious health conditions, and caregivers of people with disabilities or health conditions. Workers with disabilities often face multiple barriers to employment, and families that include people with disabilities are significantly more likely to live in poverty and lack savings. All too often, many cannot afford an unpaid absence from work. At the same time, people with disabilities and their family members disproportionately work in part-time, low-wage jobs that commonly lack access to employer-provided leave benefits. 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.

Recent years have seen a growing number of states developing paid leave insurance programs, as well as bipartisan Congressional interest in creating federal paid leave policy. A national paid leave program could complement other federal and state policies designed to strengthen employment and economic security for people with disabilities and for workers providing care for children, adults, and seniors with disabilities or serious health conditions.



Unfortunately, little research exists on the experiences and perspectives of people with disabilities and their families to help inform development of disability-inclusive 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 qualitative study involving semi-structured, one-on-one telephone interviews to

learn more about how workers with disabilities and families that include people with disabilities use, need, and can benefit from paid family and medical leave. Findings are based on data gathered from 90 interviews with workers in California, New Jersey, New York, and North Carolina who have disabilities or health conditions, provide care to family members with disabilities or health conditions, or both.

FINDINGS

WORKERS TAKE LEAVE FOR DIVERSE AND OFTEN DISABILITY-SPECIFIC REASONS.

Study participants often reported providing primary support for multiple people, and many caregivers in this study also identified 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 longer 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 also

used or expressed a desire to use intermittent leave in order to minimize time away from work. Many preferred to use fully-paid sick days, vacation days, or paid time off when possible, and used partially-paid state paid leave insurance programs as a last resort.

WORKERS VALUE THE FAMILY AND MEDICAL LEAVE ACT (FMLA) AND OTHER LEAVE OPTIONS.

Many study participants used and valued the FMLA 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 an easier and more efficient process for applying for and 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 application and process; and
- Fear of job loss (including lack of employer support and stigma against disabilities).

RECOMMENDATIONS

The primary research findings from this study informed recommendations for action by policymakers, employers, and advocates to strengthen existing paid leave programs and to advise development of a disability-inclusive national paid family and medical leave policy. 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.

"[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

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.
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 health care providers.
	Use online communities for outreach and education.
	Coordinate with service and advocacy organizations.
	Conduct outreach to health insurance providers, including managed care organizations.

INTRODUCTION

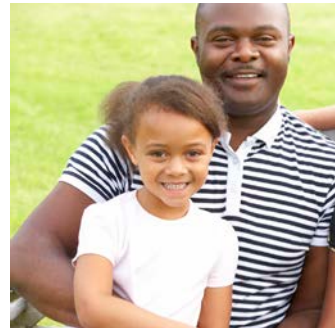
Most people with disabilities or serious health conditions are eager to work to support themselves and their families, and to contribute meaningfully to society (Kessler Foundation, 2015). Similarly, workers who provide unpaid care for loved ones with disabilities or serious health conditions typically also value both their professional responsibilities as workers as well as their responsibilities as caregivers (Horowitz, Parker, Graf, & Livingston, 2017). The successful workforce participation of people who have disabilities or of people who provide care often requires access to supports and services, accommodations, and protection against discrimination. Paid family and medical leave policies, traditionally only offered by employers but more recently offered by an increasing number of state governments, can provide additional and vital support toward maintaining employment, by allowing workers to take time away from work to address health needs. While recent policy debates on paid leave have often centered on new parents, leave policies must also meet the needs of people with disabilities and their families.

Among all workers, leaves from work are most commonly taken to address workers' own health conditions (Klerman, Daley, & Pozniak, 2012).

Roughly one in five Americans currently live with a disability (Brault, 2012), and roughly one in four households include a child, adult, or senior with a disability (Altman & Blackwell, 2016). In addition, an estimated 43.5 million adults in the U.S. provide unpaid support to a child with a medical condition or an adult, and that number is expected to rise in the coming years (AARP and the National Alliance for Caregiving, 2015). As a significant portion of the U.S. population ages, paid leave is increasingly relevant to workers in the 'sandwich generation' who find themselves caring for both elderly parents and children (Parker & Patten, 2013). Access to pay during leave for any of these purposes can be particularly important for people with disabilities and their families, who on average, have lower incomes and fewer savings to fall back on when taking leave (Grant, Sutcliffe, Dutta-Gupta, & Goldvale, 2017).

Numerous studies have shown that paid leave improves economic security, family relationships, health outcomes, and workforce attachment for new parents (see, for example, Stanczyk, 2016; Pragg & Knoester, 2017; Skinner & Ochshorn, 2012; and Houser & Vartanian, 2012). While fewer studies have evaluated the benefits of paid leave for workers who need to take time off to care for family and workers with disabilities, it is reasonable to expect that paid leave has positive impacts for these workers as well (Grant et al., 2017). The limited number of studies focusing on this population that have been conducted point to benefits in the health of the person receiving support as well as the emotional health of the caregiver (Schuster, Chung, Elliott, Garfield, Vestal, & Klein,





2009). This paper contributes to this literature by presenting new findings from qualitative research on work, caregiving, and leave experiences among people affected by disabilities and serious health conditions.¹ The findings offer an important step toward better understanding the barriers to family and medical leave and how to improve federal or state leave policies to support the workforce goals and health needs of people with disabilities and their families.

In the U.S., current family and medical leave policies are a patchwork of state and federal policies that allow eligible workers to take time off from their jobs, either paid or unpaid, to: (1) address their own serious health condition (referred to as medical leave, temporary disability leave, or short-term disability, among other terms), (2) care for a newborn or newly adopted child (parental leave), or (3) care for a family member with a serious health condition (family leave). The federal Family and Medical Leave Act (FMLA) allows workers to take unpaid, job-protected leave for all of these reasons. While national in scope, roughly 40 percent of workers are not covered by the FMLA, due to its restrictive employer coverage and employee eligibility requirements. Another federal law, the Americans with Disabilities Act (ADA), requires employers to consider allowing a worker to take unpaid leave

as a “reasonable accommodation” related to a disability, including employees who are ineligible for FMLA leave or who have exhausted their FMLA leave (U.S. Equal Employment Opportunity Commission, 2016). Beyond the FMLA and ADA, a number of states have their own unpaid leave laws, with some states expanding their eligibility criteria for unpaid, job-protected leave beyond the FMLA (Williamson, 2018).

With regard to paid leave, most workers must rely on employer policies, and as a result access is often limited. Only 39 percent of civilian workers have access to short-term disability insurance through their employer, and only 16 percent have access to paid family leave (U.S. Department of Labor, 2018a). Low-income workers are the least likely to have access to paid family and medical leave through their employers (Horowitz et al., 2017; Stroman, Woods, Fitzgerald, Unnikrishnan, & Bird, 2017).

Addressing the need for paid leave, a growing number of states are implementing paid family and medical leave (PFML) policies. These policies are often implemented through statewide and state-regulated insurance policies that provide workers with a proportion of their wages while on leave; employers providing paid family or medical leave plans in these states must provide

¹ For the purposes of this paper, the phrases ‘people with disabilities’ and ‘disability’ include people with serious health conditions. “People with disabilities” refer to participants in this study who self-identified as having a disability, a serious health condition, or both. “Caregivers” refer to participants who self-identified as providing support to a person with a disability, a serious health condition, or both. However, quote attributions use the terms ‘disability’ and ‘serious health condition’ in accordance with each participant’s self-identification.

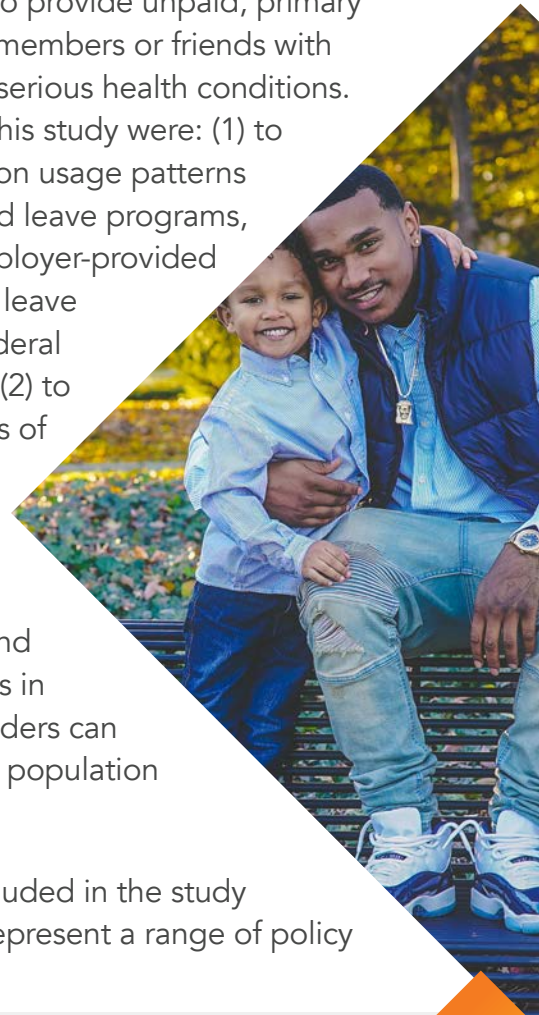
leave benefits equal to or better than state programs. These programs vary by state but are generally funded through employer and worker contributions. In this paper, state programs for leave to address a worker's own non-work related injury or illness will be referred to as temporary disability programs (reflecting the programs' names in the study states) and programs for leave to address the health of a family member will be referred to as paid family leave (PFL) programs. (See Appendix I for a more detailed description of the various state programs.)

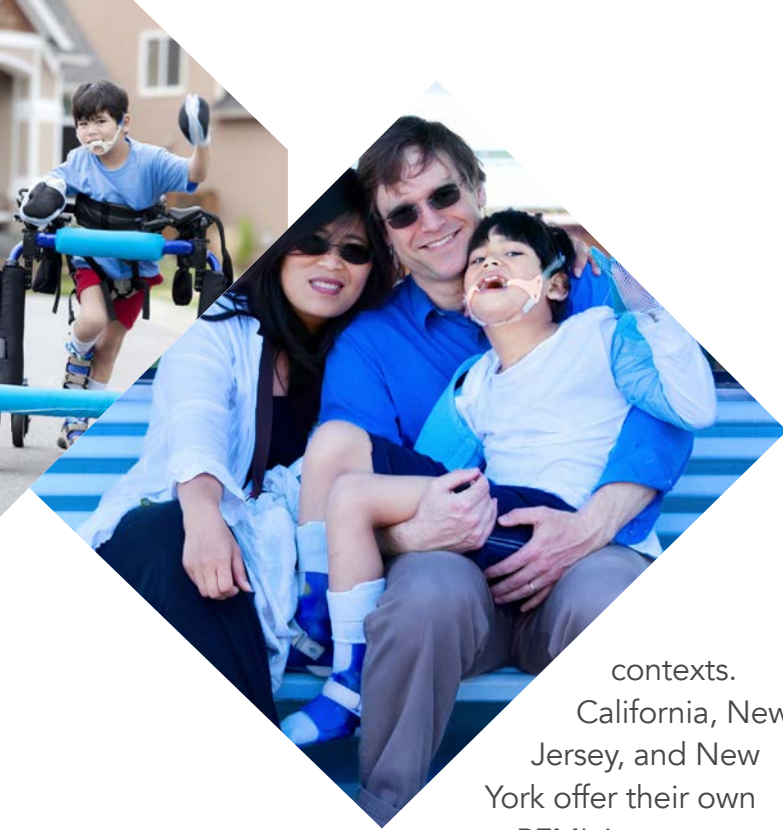
With rising interest in PFML at both the state and federal level, it is imperative to ensure that these policies are inclusive of the needs of the disability community. As mentioned above, while many studies have examined the impact of unpaid and paid leave policies on new parents and their children, fewer studies have examined how access to paid leave affects the economic security, health, and well-being of people with disabilities or caregivers of people with disabilities. These studies, however, have indicated that paid leave from work enables caregivers to provide better care for their loved ones, has health benefits to both parties, and enables workers to seek preventive medical care, among other benefits (Heyman & Earle, 2011; Peipins, Soman, Berkowitz, & White, 2012). This paper contributes to the literature by presenting findings from a qualitative study on the leave-taking needs and experiences of workers with disabilities as well as workers affected by serious health conditions. It additionally provides recommendations for how policymakers, employers, and advocates can make it easier for all workers to manage work during a stressful period of their lives related to their health or the health of people for whom they provide support. Perhaps most importantly, the findings in this study provide a blueprint for an inclusive, comprehensive national paid leave policy.

STUDY AIMS & METHODS

The Arc provided funds to the National Center for Children in Poverty at Columbia University's Mailman School of Public Health to conduct a qualitative study involving semi-structured, one-on-one telephone interviews with: (1) workers who have disabilities and/or serious health conditions and (2) workers who provide unpaid, primary support for family members or friends with disabilities and/or serious health conditions. The main aims of this study were: (1) to understand common usage patterns for unpaid and paid leave programs, including both employer-provided leave benefits and leave provided under federal and state policies, (2) to assess the priorities of working caregivers and workers with disabilities regarding taking leave from work, and (3) to pinpoint ways in which key stakeholders can better support this population of workers.

The four states included in the study were selected to represent a range of policy





SAMPLE CHARACTERISTICS

contexts. California, New Jersey, and New York offer their own state PFML insurance programs, while North Carolina does not. While California and New Jersey have had PFML programs in place since 2002 and 2009, respectively, workers in New York were only able to take advantage of family leave starting January 2018. Interviews were conducted over the course of 6 months during the summer and fall of 2018. Researchers asked study participants about their experiences managing work and their own health needs as well as the support they provide for others. Transcripts of the interviews were analyzed using a combination of Framework, a qualitative approach employed for applied policy research questions, and Grounded Theory, a method involving constant comparative analysis (Ritchie & Spencer, 2002; Corbin and Strauss, 1990). As with all qualitative studies, findings cannot be generalized, but point to issues relevant to the sample populations. *(See Appendix II for a more detailed account of study methods.)*

The study sample consisted of 90 individuals from California, North Carolina, New Jersey, and New York. All participants were screened over the phone or via an online survey to ensure that they: (1) worked in the previous two years in one of those four states, and (2) identified as someone who (a) had a disability or serious health condition; and/or (b) was in the previous two years the primary, unpaid caregiver for a friend or family member with a serious health condition or disability. Half of the study participants (45 participants) provided support for someone with a disability or serious health condition and reported not having a serious health condition or disability. The other half of the study participants (45 participants) identified as someone with a disability and/or serious health condition, among which 34 participants (76 percent of workers with disabilities and/or serious health conditions) also provided caregiving for a loved one with a disability and/or serious health condition. In total, then, 88 percent of participants (79 participants) reported providing some form of caregiving support. Study participants were not given a specific definition of disability or serious health condition, but self-identified or identified the person for whom they provide care as such and offered additional information on the nature of their condition(s) and condition(s) of the person.

The majority of participants worked in the private or nonprofit sector, were female (87 percent), U.S.-born (91 percent), identified as “white” or “Caucasian” (70 percent), and earned below the state median household income for their family size and state of work (57 percent). (See Appendix II for additional sample characteristics.)

PARTICIPANTS PROVIDING SUPPORT

As described above, 79 participants reported providing primary caregiving support² to someone with a disability or serious health condition, including 34 people who also reported having a disability and/or serious health condition themselves. Most of the sample (49 participants) reported caring for at least one son or daughter. Twenty-one percent of participants (19 participants) provided care for more than one person. Notably, 23 percent of participants (21 participants) reported providing support to a person not traditionally covered under the definition of family under the FMLA, including siblings, grandchildren, and friends.

Participants provided support to people with a wide range of disabilities and conditions, including autism spectrum disorder, Down syndrome, intellectual disability, cerebral palsy, spinal muscular atrophy, depression, schizophrenia, anxiety, Alzheimer’s, dementia, multiple sclerosis, cancer, visual impairments, mobility limitations, chronic obstructive pulmonary disease (COPD), transient ischemic attacks (TIAs), and some rare conditions, among many others.

The most commonly reported types of support that workers in the sample provided were transportation to doctors’ appointments and activities of daily living, such as assistance with bathing or eating. A number of respondents also reported that they assisted with coordinating health care, advocating for their loved one at hospitals and doctors’ offices, researching and understanding treatment options, and applying for health insurance and other benefits like Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). The intersection between the types of support caregivers identified as providing and the reasons that caregivers took leave is discussed in the Findings section below.

PARTICIPANTS WITH DISABILITIES

As with people for whom caregivers identified as supporting, participants in this study identified as having a wide range of disabilities, including autism spectrum disorder and associated co-occurring health conditions, Down syndrome, other disabilities related to cognitive impairment, cerebral palsy, spinal muscular atrophy, depression, schizophrenia, anxiety, Alzheimer’s, and dementia, multiple sclerosis, cancer, visual impairments, mobility limitations, and transient ischemic attacks (TIAs). Appendix II includes a complete roster of health conditions and disabilities reported by participants in this study.

² Participants classified as caregivers are people who answered “yes” to the question “Do you provide support to someone with a disability or serious health condition?”, with the term “provide support” defined as “serving as someone’s primary support person.”

FINDINGS

REASONS FOR LEAVE AND PATTERNS OF LEAVE-TAKING

Worker interviews revealed multiple challenges that people faced as caregivers and as workers with disabilities. The reasons people needed to take leave, their experiences taking leave, and a range of other factors affected participants' ability to access paid leave. In total, 71 percent of participants took leave for a period longer than "a few"³ days over the prior two years to address their own health condition or provide support for a family member or friend. This includes 26 percent of participants who took a leave from work for a period longer than "a few"⁴ days to address their own health condition, and 62 percent who took a leave from work longer than a few days to provide support for a family member or friend, including for a newborn.⁵ As the sample included people with disabilities who were also caregivers, these groups are not mutually exclusive: 17 percent took leaves from work to address their own health condition and also to provide caregiving support.

³ Participants, or people who explicitly gave their consent to participate in this study, were asked whether they had taken off work for more than "a few" days at a time; these numbers are based on responses to that question.

⁴ See note 3.

⁵ Participants who took leave to bond with a child were only included in the study if they identified as someone with a disability and/or serious health condition or if they provide support for someone with a disability or serious health condition, which may or may not have been the newborn.

REASONS FOR LEAVE RELATED TO CAREGIVING

Across all groups, the most common reasons participants took leave were for doctors' appointments for themselves or for the person(s) for whom they provide care. Participants took leave due to the person's illnesses, treatments, surgeries, and medical emergencies. Several participants reported taking longer leaves to learn about a new diagnosis and treatment options, which sometimes entailed visits with multiple specialists. For example, one participant recounted how she took a four to six week leave of absence after her daughter was diagnosed with a mood disorder and anxiety:

"It was several years ago when I took a personal leave of absence. Everything was falling apart. [My daughter] was falling apart. I had this huge job. I was trying to care for her and her brother and my parents. I was exhausted. I needed to have more time to talk to doctors, understand treatment and medication. We were crumbling, and so was she. I couldn't juggle the two anymore, with how tired I was on top of that... There's a lot to learn when your child has a lot of mental health issues. Not only do you have to learn it. You have to believe it. Once you believe it and have learned it, you have to help the rest of your family – because I also have a son – be more empathetic of some of the behavior [they were] seeing."

North Carolina caregiver



Many parents of school-age children reported an additional need to take leave for Individualized Education Program (IEP) meetings, which are crucial to ensuring a quality education for children with disabilities. Caregivers also spent significant time advocating for services, including meeting with case workers.

“I’m using time today to have a meeting with his case worker, because he’s been denied for speech therapy. I was told that ‘he is on par for his disability, and since he has Down syndrome, he might not talk, it wouldn’t even really be worth it.’ I pushed back and got an evaluation done, and we’ll be finding out the results of the evaluation today. And the same thing happened for OT [occupational therapy].”

New Jersey caregiver

Others also recounted using leave time to arrange care and treatment and understand options for paying for care. One participant recounted his experience taking four months of FMLA leave to arrange care for his elderly father who was diagnosed with dementia and lived across the country.

“We helped activate his long-term care insurance... I ended up going to about 60 or 70 doctor’s appointments over the course of three months with him. Then establishing care for him in his new area where he was living, while my sister, both of us researched places for him to live, in assisted living. Then we had to hire movers and move as much of his stuff over to the new place as we could. The following year we sold his house and had to clean it up... All the while, of course I’m also taking his daily phone calls, reminders to go to appointments and to be ready for them.”

New York caregiver with a serious health condition

Sometimes, leave needs were unpredictable. At times, participants needed to take leave if other care providers fell through or, for parents of school-age children, if it was summer and care options outside of school were difficult to arrange. Many parents of school-age children also reported occasionally needing to pick up their child due to behavioral issues at school.

REASONS FOR LEAVE RELATED TO A HEALTH CONDITION OR DISABILITY

Similar to caregivers, the most common reason people took leave to attend to their own health needs was for doctors’ appointments. Participants also recounted needing leave to recover from an accident, surgery, or other hospitalizations; to receive treatments from specialized hospitals or facilities (occasionally far from the participants’ residence); or for childbirth- or pregnancy-related reasons.

“Part of my treatment plan is that I spend a day in the hospital every seven weeks. Those days are non-negotiable and I will not be here [at work].”

North Carolina caregiver with multiple sclerosis

One participant with spina bifida recounted that her leave following childbirth took longer than most women due to her disability.

“I had to have an unplanned C-section, and because of my disability there were some complications. It took me a lot longer to recover.”

New York worker with spina bifida



While doctor's appointments and surgeries were often predictable, participants could not always plan for absences related to their health conditions. For example, participants with chronic conditions like multiple sclerosis, rheumatoid arthritis, migraines, or anxiety and panic disorders sometimes experienced irregular flare-ups of their condition that required leave from work.

"Now I take oral chemo every day, which is why I'll be fine for weeks or months and then be sick one day. It's a part of how things go with the medication...I don't pick the days I get sick. It's just how my body reacts to the medication."

New York worker with bone cancer

LEAVE-TAKING OPTIONS

Study participants used similar strategies to take time off from work. Participants with access to employer-provided paid time off (PTO), including sick days, vacation, or personal time, often chose to take PTO instead of unpaid FMLA-covered time or PFML, especially if leave was intermittent or unpredictable. Some study participants were able to work out formal or informal arrangements with their employers that provided them flexibility in their work hours or the ability to work from home. Other employees who did not use PTO were able to access unpaid FMLA leave alongside state-regulated PFML programs. People who provided support to multiple people and/or had serious health conditions also reported not having enough time off for an "actual vacation" because all their paid time off, including vacation time, went to caregiving or health needs.

"I wish I could preserve my vacation time so that I would have some actual rest, some paid rest."

New York caregiver providing support for her husband and son

Anticipating their need to take time off from work, a number of study participants had submitted certification for an ongoing serious health condition (their own or another's) that qualified for the FMLA, so that they could take job-protected leave if they unexpectedly found themselves needing to take leave for an FMLA-covered reason.

"The staff person my mom has is wonderful, but nevertheless she needs to take breaks and vacations, and so I need to fill in those time periods. And then I wanted to have [FMLA] in place, because at some point in time something more will happen, and I have to sort of be ready when that time comes to be able to be there for my mom."

New York caregiver with a disability and serious health condition

"[My] favorite thing about FMLA is that I'm able to do it at [the] split of the moment and that it's not held against me."

New Jersey caregiver with a disability and serious health condition

Many study participants chose jobs with flexible schedules or self-employment to accommodate their health needs and their caregiving responsibilities. As discussed below, it is significantly more difficult for self-employed individuals to access state PFML. For many, however, being self-employed was the only way to earn an income and meet the high leave-taking demands of their caregiving situation.

“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 it.”

New York caregiver with a disability and serious health condition

A teacher in this study reported that she left her teaching position because she could not walk up and down the stairs in the school.

“[I left that position] Because of my disability... We had an elevator in the school, but the principal wouldn’t let me use it. I just left the job. I didn’t know about all the accommodations.”

New York caregiver with a disability and serious health condition

WORKPLACE ACCOMMODATIONS AND FLEXIBLE SCHEDULING

Despite the loss of employer PTO and reduced access to state PFML resulting from self-employment, workers with disabilities or caregivers may choose self-employment (or become unemployed) because they are unable to find workplaces that accommodate their disabilities or offer schedules that are flexible enough for caregivers to address the needs of their loved ones. Study participants mentioned how they could have better balanced their work and caregiving responsibilities or their health had their place of employment been more flexible or accommodating. One participant mentioned that despite being able to fulfill her job responsibilities from home, her company did not allow her to do so. Another participant who experienced migraines requested access to her computer’s settings to reduce the screen’s glare when she was first hired by her company but reported that her company did not accommodate this request. She ended up quitting this job due to this easily rectifiable issue.

“I was getting sicker and sicker with migraines, and they wouldn’t [give me] access to the control panel to change the computer they provided.”

North Carolina caregiver with a disability and serious health condition

Still, others recounted how their employers were accommodating and felt lucky to have supportive coworkers, indicating that workplace support can make a big difference in people’s ability to not only access leave, but also stay employed.

“Where I work, they’ve been unbelievably outstanding with accommodations. That’s one reason why I like and have continued to work there. They go out of their way, above and beyond, to do everything they can to accommodate my needs as [a] physically-challenged person... Sometimes people will move my car for me. The handicapped parking isn’t as close as I’d like it to be. I have some friends who will get my keys and move my car to a closer spot.”

New Jersey caregiver with a disability and serious health condition, including mobility impairments

BARRIERS TO LEAVE

For those workers who were unable to access enough paid or unpaid leave, the consequences were devastating, ranging from increasingly poor health to the loss of their job, or





unsafe care situations for their family members.

“I monitor his quality of life as much as possible, and I want him to be as safe as possible. I don’t really have any support for that. I go to the doctors and tell them that I come home from work and he’s wandering down a six-lane highway because nobody’s come with him when he gets home from the [community center]. He set the kitchen on fire one time... It’s very clear that he should not stay at home [alone], but I don’t get any support.”

North Carolina caregiver and worker with a serious health condition, providing support for her husband

Participants reported multiple barriers to accessing paid or unpaid leave, including a lack of awareness of state and federal programs, inadequate wage replacement levels in some paid leave programs, not being eligible for job protection, not being eligible for paid leave programs, and bureaucratic hurdles.

AWARENESS: A number of participants appeared to be confused by or unaware of state family and medical leave programs. Many participants had heard about their state’s program in relation to having a child but did not consider that the program could be used for their situations as well. Several participants also reported feeling too

overwhelmed at the time they needed leave to research and understand their options.

“Someone had said there is a short-term disability something, but by the time I felt it was relevant to my life I was too sick to do the research myself.”

North Carolina caregiver with a disability and serious health condition

Some who did take a leave were not informed by their employers about their options to take leave under the state programs or were given incorrect information about the programs.

“New York state has short-term disability, which I wasn’t aware of until after it was all said and done over the years. One of the other [employees] asked me if I had gotten paid for that time, and I said no, and she found that to apply for NYS Disability, your employer has to give you some papers...but we never got any papers, because they knew we were going out, and she’s been out several times for surgery.”

New York worker with a disability and serious health condition who took an extended, unpaid leave of absence from her job

“So I was told about New Jersey Family Leave Insurance, but I was not given correct information about it [from my employer] until I was already out on pregnancy leave... finally, after a series of frustrating phone calls, I found that I had been receiving conflicting information from the multiple people I had spoken to. I asked to speak to their manager’s manager, who finally sat down and scheduled time to talk with me for almost 40 minutes about what New Jersey Family Leave entailed, how it was different from the standard short-term disability leave and how I could apply for it. Then I had to go and call the New Jersey Family Leave people to get more definitive information, because the people providing the [Human Resources] services for my company couldn’t give it to me.”

New Jersey caregiver

Workers who did not know about leave programs or protections often expressed that they would have considered taking advantage of them if only they knew what the programs offered.

“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...that’s what I had to do rather than being able to do the opposite, rest and then come back restored and replenished.”

North Carolina worker with a serious health condition

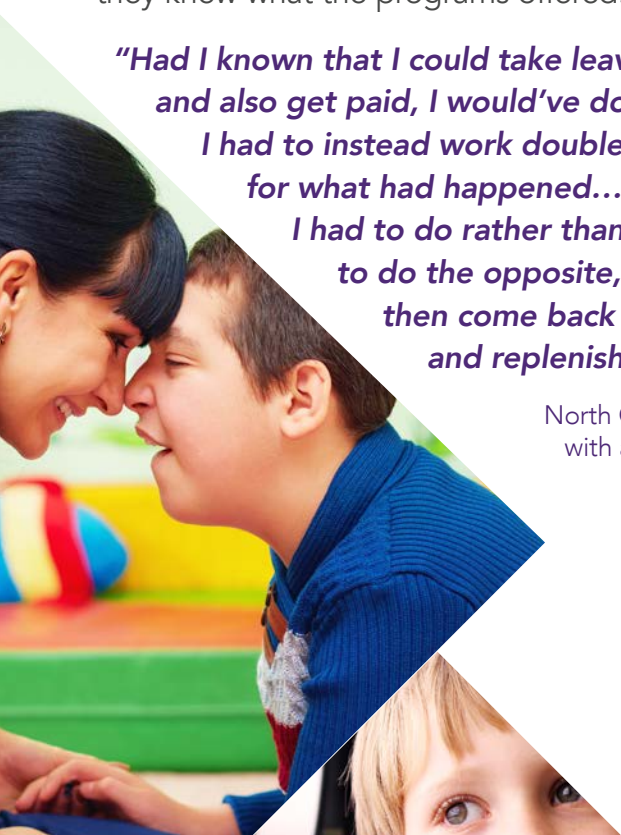
WAGE REPLACEMENT: If working in a state with a PFML program, eligible for that program, and aware of it, people whose employers provided paid time off typically chose to use their employer-provided time for a range of reasons. For example, among study participants who were caregivers, lived in a state with paid family leave, and who had jobs outside the public sector (meaning that they were likely eligible for paid family leave), only 10 people took up the state’s paid family leave program outside of any employer PTO for caregiving reasons, compared to 40 who reported not utilizing the state program; among those 40 caregivers, 29 reported taking leave for longer than a few days to provide caregiving support. Many participants reported that they did not want to forgo income; current PFML programs only provide 50 to 70 percent of a worker’s average wages. Participants seemed to use PFML programs as a last resort, when they did not have employer-provided leave at full pay available to them.

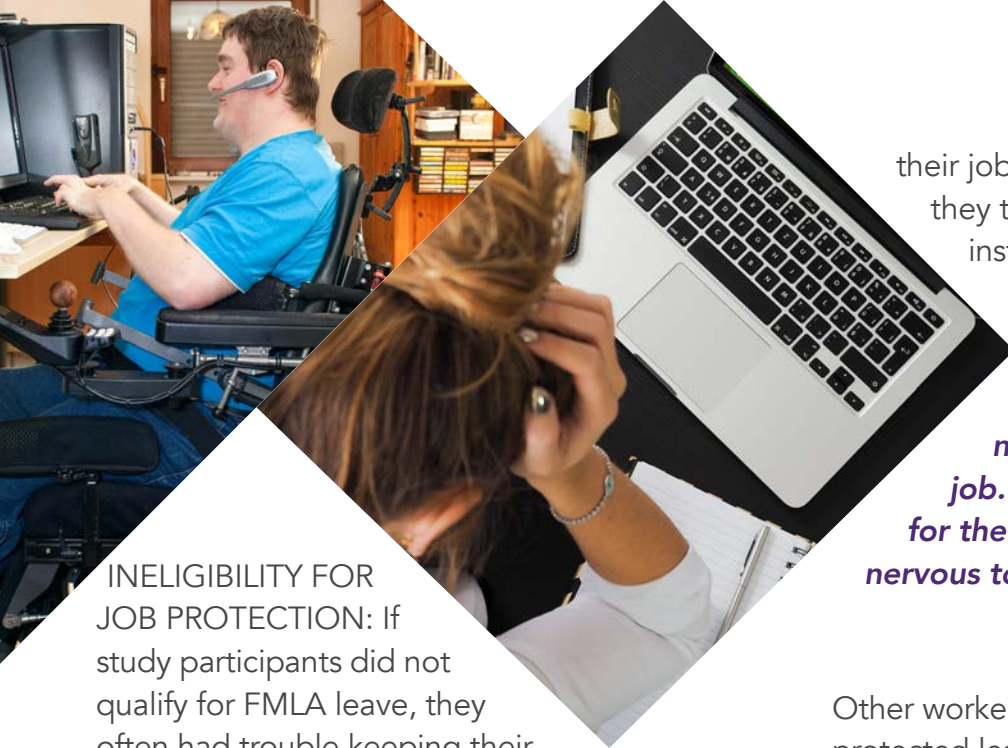
“The FMLA only protects my job, but my job isn’t in jeopardy, thankfully. So I don’t have to worry about that piece of it. Even from a personal standpoint, I have to use my time first because I need to be paid at 100% wages, not 60% wages, in order to pay my bills.”

New Jersey caregiver

“The waiting period [for state temporary disability] is so long, and the amount of money you get is so little. I would’ve utilized it [only] if I would’ve exhausted every other benefit I’m eligible for.”

New York caregiver with a disability and serious health condition





INELIGIBILITY FOR JOB PROTECTION: If study participants did not qualify for FMLA leave, they often had trouble keeping their jobs. One participant reported needing to take intermittent leave due to her mental health issues. She could not, however, because she had only been at her job for just under three months; her employer only allowed workers to accrue employer-provided time off after 3 months of employment, and because she had not yet been at her job for a year, she did not qualify for time off under the FMLA. Since she was working in North Carolina, she also had no access to state job-protected, unpaid leave or to a state paid leave program. She later quit her job to take a low-wage, tipped job that afforded her more scheduling flexibility:

"It's a question of just having a job in general. You take what you can get. [With this new job] I can log in for work and log out when I'm ready to go home...that's the tradeoff of working a low-paying, tipped job."

North Carolina worker with a disability and serious health condition

Some states' paid leave policies include job protection while on leave. In states that do not, however, one barrier to paid leave was that people who were not simultaneously eligible under the FMLA were concerned about keeping

their job and associated benefits. As such, they typically chose not to use PFML and instead used their sick or vacation days.

"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

Other workers reported being unable to take job-protected leave because they were taking leave to provide support for a person who did not clearly fall under the FMLA's definition of family member.

"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

Technically, the FMLA covers more relationships than parents, children, and spouses, and in 2015 the U.S. Department of Labor (DOL) clarified how additional "in loco parentis" relationships are covered under the law, including when an individual assumes day-to-day responsibilities and provides significant financial support to a sibling, family member, or other loved one who has a disability (Sibling Leadership Network, 2015; U.S. Department of Labor Wage and Hour Division, 2015). While this definition may have covered the care provided by some caregivers in this study who were not the parents, spouses, or children of those they supported, the DOL guidance on "in loco parentis" is vague and explicitly open for interpretation, leading to confusion among many employees and employers (Sibling Leadership Network, 2015b), likely

including the California caregiver quoted above.

INELIGIBILITY FOR STATE PFML PROGRAMS:

A number of study participants were self-employed, freelancers, or public employees, all of whom are not universally covered by all state PFML programs. Eleven participants reported being currently or previously self-employed and 26 participants reported being currently or previously public sector employees.

Furthermore, many participants expressed confusion over whether they were eligible for leave under these state programs.

“It’s very sticky to have to take time under a protected leave to care for a child because the verbiage in [New York’s Paid Family Leave Program] reads that it’s for a recurring medical condition. Legally the definition is if they’re seen by a doctor and if their condition is long-term and if they have to be seen by doctors regularly, then you could meet the criteria, but 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 and doctor’s appointments, are a medical condition.”

New York caregiver with two minor children with disabilities

As with the FMLA above, others in the study reported providing care for someone that they were not sure was covered under their state program’s definition of family for family leave.

“I’m hoping to take family leave [to care for my nephew], but I don’t know if it’s going to qualify, but I’m going to try, but I might have to take time off without pay.”

California caregiver with a disability

GOVERNMENT AND EMPLOYER BUREAUCRACY:

People often reported that information about leave programs they received from the government or their employers was confusing or inconsistent. For some workers, this posed a barrier to understanding that they were eligible for a state PFML program or to using the program. In addition, workers who used state PFML programs valued being able to take time off with some pay, but also reported some problems with their applications, confusion over eligibility, and delays in payments.

“When I applied for PFL, they took almost a month to approve it, and despite turning in the paperwork the same day, it was far more sporadic. 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. I went to the EDD [California’s Employment Development Department] office and asked to speak with someone, because 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 address a husband’s injury

“I ... prefer to work rather than deal with all this paperwork and not be working.”

New York worker with a disability and serious health condition

Moreover, while many participants largely trusted governmental sources of information (see below for more discussion on sources of information), several



people also reported being confused and desiring information about government programs that was clearer and more accessible. Also, many reported receiving no information or insufficient information about leave options from their employers.

"[I found out you could take paid family leave intermittently] from a coworker. Nobody else told me that [taking leave intermittently] was an option..."

California caregiver who took leave to bond with her newborn

One notable exception was the New York state website for its PFL program.

"I was pleasantly surprised by how easy [the NY state website] was to understand, and it seemed pretty user-friendly. There were pictures and colors that made it engaging. It wasn't boring. It was easy to understand and engaging. It was disappointing to realize it didn't apply to me."

New York worker with a disability, who had experienced a qualifying event prior to NY PFL implementation

STIGMA AND FEAR OF JOB LOSS: Many participants – both workers with disabilities and workers providing care – reported feeling uncomfortable informing their employers about their need to take leave. This caused many workers to hesitate before asking for leave. Participants expressed a desire for more understanding and empathy in the workplace for their disability, health, and caregiving situations.

"[People] don't recognize the reason I should take some time off [is] because I have a child with a disability, especially since it's a hidden disease. He's not in a wheelchair, on oxygen or anything like that. If it was more visible, then people wouldn't ask me."

New Jersey caregiver with a serious health condition, providing support for a child with autism

"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

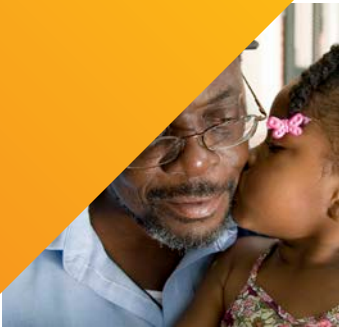
"Especially given my condition was mental health and anxiety, I feel like maybe I'm perceived to be weaker and unable to do anything, but I fought for my rights. I'm still working at the job."

New York worker with mental illness

In general, participants were concerned about how taking leave would affect their professional advancement. Several participants also cited examples of how taking leave had, in fact, damaged their career trajectories. Participants were also concerned that their need to take leave would cause them to be seen as a less valuable employee and feared that their need to take leave would put their job at risk.

"Whenever you step away from your company, I think you stop momentum, and you stop potential...any kind of promotion I might've been up for was delayed for another two years. Any project that you might've been considered for may have shifted to somebody else who was healthy and available to work on it. Then therefore they get the exposure working on that project, and you miss out."

New York caregiver with serious health conditions



“When you have to go and take a leave, that can completely disrupt the very tenuous space that you occupy...and it’s scary... In my case, [I’m] going to work day after day with half a brain on my job and half a brain on my pain, because [I’m] terrified that if [I] don’t do it, [I’m] going to be out of a job. It’s not a good feeling to be in that situation.”

New Jersey caregiver with a serious health condition and disability (rheumatoid arthritis)

This fear caused some to stay at work even while sick, or to take as little time as possible even when going to work might be detrimental to their health or the health of their family members.

“I’ll go to school sicker than a dog, and I’m that person that unless I can’t get up, I show up because my [students] are really hard for other people to take. I know nothing happens if I’m not there. It’s a wasted day. I’m one to go in if I’m needed. If I’m not dying on the floor, I usually get up and go.”

New Jersey teacher and caregiver with lymphedema

In California, New Jersey, and New York, the state’s current PFL program was built by adding onto a longstanding state temporary disability program that has retained its name. Some participants chose not to apply for these state temporary disability programs because they did not identify as a person with a disability. A few participants were concerned that applying for a

program with the word “disability” in the name would hurt their future employment opportunities.

“When the employer gave me the [disability benefits] form, it seemed like it was more permanent. So if I fill it out, like I’m considered disabled by the workforce, by the employer, and that I will be out for longer time. Meanwhile, I needed a couple of weeks, three weeks to just start my treatment, get rest and feel better about the situation.”

New York worker with anxiety and panic disorders who decided to use FMLA over state disability benefits

VALUING WORK

Both workers with disabilities and caregivers expressed a strong commitment to work as not only a livelihood, but also a source of pride. People valued being seen as honest and hardworking employees. In fact, many felt that they had to work harder to be seen as a valued employee because of their occasional or frequent leaves from work.

“I’m not a time abuser. I’m hyper aware of the amount of time that I have to take, because I do have to take so much...I feel extremely uncomfortable taking time off, so I try not to do it as much as possible.”

New York caregiver, providing support to 2 minor children with Tourette’s and autism

“We don’t want to stay home and have the government support us. We want to support our family.”

North Carolina caregiver to daughter with seizures

“I view myself as a good employee. I love my job. I have done this for a long time. I certainly don’t shirk my responsibilities, so it’s starting to make me sort of angry that when I have a need and when I have time on the books to meet that need, [being denied requests for leave] is a form of disrespect as if my needs don’t matter.”

New York worker with a neurological condition who also provides care for her elderly mother with memory issues

“I wouldn’t use [leave time] unless there came a time I really had to do it... I also feel like I have a responsibility to my team and so I tried to be there. If I can manage it, I want to manage it, so I can meet all my responsibilities.”

New Jersey caregiver

TRUSTED SOURCES OF INFORMATION

Collectively, participants trusted information they received from other people in similar situations, health care providers, organizations that specifically serve people with a relevant health condition or disability, and trusted service

providers. As detailed above, many participants discussed trusting government sources, but had difficulty understanding the information presented to them by government officials, brochures, or websites. Others who had a high level of support from the workplace reported receiving useful information and resources from work, especially if they worked at an organization that serves people with disabilities.

“I’m almost luckier than most because I have the availability to speak to people who have familiarity with my condition at any given point in time. Also, given that they are a healthcare-related company, their drive towards supporting people with chronic healthcare issues is higher than at any other company I’ve ever worked at.”

New Jersey caregiver with rheumatoid arthritis

When asked for suggestions for how to educate people about the FMLA and state PFML programs, people mentioned a wide range of media, community, medical, and governmental sources through which to relay this information.

“Fliers, mailing stuff out, letting employers know this needs to be done.”

New Jersey caregiver

“For people with sensory disabilities, obviously the modality of the information needs to reflect that. If it’s people with neurodevelopmental conditions, then simplified language. As far as notifying them, I think we could do a better job of incorporating this information into transition plans for students in K-12 education. If a person has an IEP or a 504...they’re required to have a transition plan, which can be as little as getting a job or extensive planning for a

full-time, 24-hour placement. If schools do this for 60% of their IEP students, they get \$6,000 for teacher training. I think that would reach the greatest number of people."

New York caregiver with a disability

Since people in this study population also often interacted with multiple federal and state offices, many suggested conveying information about leave programs to these offices, such as government offices that serve people with disabilities (e.g., New Jersey Division of Aging Services, Council on Developmental Disabilities).

"I think you would reach more people if you went through schools on a special education level to let them know that [a paid leave program] is available...if somehow through the Department of Education it could be filtered down to parents of children with special needs, that would be a huge help... it would need to come from a statewide organization, maybe even [the Division of Developmental Disabilities] and Perform Care [the state's program that serves children and adolescents with health care challenges] should let their participants know."

New Jersey caregiver of a minor child with Down syndrome

Many also suggested posting information on social media websites.

"The most useful place we've found [for resources] are a couple of Facebook groups for parents of kids with disabilities and medically fragile children. They go together. One was specifically for North Carolina, so most of the information we've gotten is from other parents in situations similar to ours."

North Carolina caregiver

VALUING LEAVE

Participants who were able to take leave either through the FMLA or their state's program valued their ability to take leave and expressed gratefulness to their employers or work situation for being able to do so.

"FMLA is really one of the only safety guards that so many families have to help them... That's why I think it's a wonderful program and I'm very thankful that we have it."

North Carolina caregiver of a son with intellectual and developmental disabilities

"State programs where I can take the leave in days has been helpful, because I think I'm going to have to have my knee replaced in the next six months to a year. And that will take a lot of my sick time, so knowing that state program is there, I can take that leave and get some money from that rather than have a huge loss of income...I think the state program is really the best thing. Because of the nature of [my grandson's] disability, it's not chronic. He's not having to go through surgery. His is low-maintenance stuff that happens. I think the state program that's come out is going to be the most help."

New York caregiver with a disability and serious health condition

Many study participants were grateful for being able to take time off for less than one day at a time. While taking leave for less than a full day at a time is protected under the FMLA, and is covered under California's paid family leave law, employees are not compensated for leaves less than a day at a time under other state laws, including New York's and New Jersey's laws.

“It’s also convenient being able to take one, two or three hours of FMLA, or whatever it might be. Taking a full day, that might be a little rougher.”

New Jersey caregiver with a disability and serious health condition

“I chose to work half days five days a week, and that helped me get out of the house and to feel like I got something accomplished. For paid family leave by that point my child was home...I’d come to work four hours a day, accomplish something, go home and bond with my baby and be present for that.”

California caregiver of spouse who suffered a severe injury, who had previously used paid family leave to bond with her newborn

In particular, the flexibility of the FMLA allowed many participants to stay at work and effectively manage health needs.

“Yes, I have FMLA. I’ve had it for eight or nine years. If I have doctors’ appointments, I have some sciatica and some nerve pain and numbness in my left foot where I can barely feel my foot. I get excruciating pain. If it’s too much, I’ll take a day or go in a couple hours later.”

New Jersey caregiver with a disability and serious health conditions

The above findings highlight that workers who have disabilities and/or who care for people with disabilities can benefit significantly from leave policies that are comprehensive, accessible, flexible, and inclusive of their diverse experiences. However, the multiple gaps and barriers to leave-taking experienced by study participants highlight that while outreach and education efforts are important, increasing awareness of existing programs is not enough. The experiences of people interviewed also pinpoint ways in which policymakers and program administrators can enact and help enforce policies that are more comprehensive and inclusive of leave-taking patterns and needs, as well as how employers and advocates can better support workers with disabilities and working caregivers of people with disabilities. Recommendations for policy and practice are detailed below.



RECOMMENDATIONS FOR POLICYMAKERS

The experiences of workers in this study reveal a number of strengths and shortcomings in current state paid and unpaid leave laws as well as the FMLA. This section outlines recommendations for federal policymakers as well as state and local policymakers and program administrators. Federal policymakers should apply lessons learned through state programs to the development of a comprehensive national paid leave policy. Policymakers in states that have not already passed paid family leave legislation should work to pass such legislation, similarly building upon these lessons learned and best practices in other states. State and local policymakers in jurisdictions that already have passed paid leave legislation should consider ways to ensure robust coverage, eligibility, and flexibility as they create new leave programs or strengthen current programs. State and local PFML program administrators should also work to streamline PFML applications and enhance public information and access.

1 *Create a comprehensive, inclusive national paid leave program.* This study's findings reveal how workers access and use state PFML programs, how the FMLA protects workers across state lines, and how workers with disabilities and caregivers could be better supported in their health and financial well-being.

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

While state PFML programs provide compensation for individuals covered under those programs who would not otherwise be able to utilize employer PTO for leave needs, this study's findings also highlight the many gaps and barriers that exist even in states that offer PFML programs. A well-publicized, inclusive, and robust national paid leave policy would enhance access to paid leave and remove considerable confusion among workers who currently face an alphabet soup of various state paid leave programs and federal unpaid leave policies. A comprehensive national PFML program would also address the confusion and difficulties that many participants in this study experienced when attempting to apply for leave or determining which policies were applicable to their current situation.

"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 a disability



Labor Wage and Hour Division, 2011). (Here and elsewhere, these protections are referred to collectively as “job protection.”) When eligible, workers can take paid leave concurrently with FMLA leave to secure the benefits and protections of both. However, many people in this study did not qualify for FMLA leave because they did not work for an FMLA-covered employer or did not meet FMLA employee eligibility requirements. For example, some study participants had not completed a year at their jobs before their need for leave arose, worked for an employer with less than 50 employees, or had not worked enough hours.

Ultimately, policymakers have the power to address structural barriers to leave through comprehensive, national, policy reform. If a national paid leave program was implemented incorporating the further recommendations below, paid leave programs will be more accessible and less burdensome to both employers and workers alike.

“FMLA is really one of the only safety guards that so many families have to help them. If [someone is] working with a smaller company and once again they’ve got a boss or a supervisor who isn’t supportive and not understanding of what that individual is going through, they can make life a little more difficult for that parent... I think it’s a wonderful program and I’m very thankful that we have it, but I think that it could help do more.”

North Carolina caregiver

2 Provide job protection for paid leave programs. A worker who takes leave under the FMLA is guaranteed several important protections, including job restoration or the right to be reinstated to their position or an equivalent position upon return to work (U.S. Department of

Neither California’s nor New Jersey’s PFML programs provide job restoration or other protections for program participants. While New York’s PFL law includes job protections, such protections are not afforded under the state’s temporary disability insurance (TDI) program, which allows workers to take leave to address their own disability or illness. People who use New York’s TDI program or workers who use PFML programs in New Jersey and California may have job protection under paid leave programs only if they also qualify for the FMLA, ADA, or an equivalent state-level protection. (See Appendix I for more details on how these programs interact.)

Since state PFML programs include more expansive coverage and eligibility than the FMLA, providing job protection under PFML programs would close an important gap for people who are ineligible for FMLA leave and would reduce a major barrier to state PFML program use. However, including job protections in state paid leave policies would only help address the leave-taking needs of residents in states that have the political will to implement paid leave policies. A national paid leave program should include

strong protections, including job restoration, so that workers in all states who need to take leave can do so without putting their jobs at risk.

3 Include anti-retaliatory provisions.

Related to job restoration, study participants also expressed reluctance to take advantage of leave programs because they were concerned that it would jeopardize their career or that they would be perceived or treated differently for requesting leave, or upon returning from leave. Retaliation includes actions taken by employers to punish employees for taking leave, even if those employees were reinstated into their previous positions or an equivalent position. Indeed, some participants who did take leave recounted negative experiences returning to work.

“When I requested the leave and the clinical director told me to talk to HR, a couple months after I had a very negative evaluation by two of the most important people at the job I did. They told me it wasn’t personal and that every other counselor in my position was getting [the same treatment]. But I talked to some other people, and that wasn’t true.”

New York worker with a disability

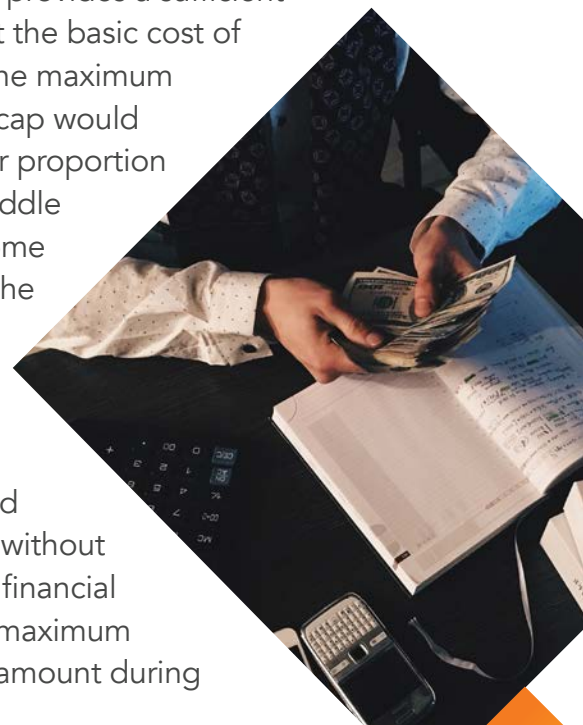
In addition, anti-retaliatory provisions in the FMLA prohibit the employer from firing an employee for requesting leave rights and prohibit the employer from discriminating against an employee in any other way because that person has requested FMLA leave, inquired about the FMLA, or complained about an employer’s violation of the FMLA (U.S. Department of Labor Wage and Hour Division, 2011). Anti-retaliatory measures are also included in the ADA, New York’s Paid Family Leave and Disability Benefits Law, and San Francisco’s Paid Parental Leave Ordinance (City and County of San Francisco, 2017). However, New Jersey’s and California’s PFML programs do

not contain such guarantees, and not everyone who is eligible for paid leave benefits is covered under the FMLA. Such anti-retaliatory provisions should be expanded to paid leave programs as well.

4 Ensure sufficient wage replacement and maximum benefits.

Since PFML benefits in California, New Jersey, and New York only replace a portion of their paycheck, many workers in this study found that taking leave using state PFML programs was not financially feasible. As a result, many returned to work before they were ready or used their employer-provided time off for caregiving or to address a serious health condition. Currently, wage replacement through state PFML programs is a percentage of a worker’s average weekly pay up to maximum cap (see Table on page 26A). Policymakers should consider providing weekly PFML benefits as close to 100 percent of a worker’s average wages as possible, prioritizing lower-earning workers who live paycheck to paycheck.

In addition, policymakers should consider ensuring that the PFML maximum weekly benefit amount provides a sufficient income to meet the basic cost of living. Raising the maximum weekly benefit cap would replace a higher proportion of wages for middle and higher income workers. From the table on the following page, it is clear that for New Yorkers and New Jerseyans without other means of financial assistance, the maximum weekly benefit amount during



leave is not enough to meet basic expenses during their leave time (Economic Policy Institute, 2018). Furthermore, the estimated costs below are for all families, and are not specific to families that include people with disabilities or serious health conditions. Weekly costs are no doubt higher for families who incur additional expenses due to medical or disability-related expenditures.⁶ Federal policymakers should take into account the amount needed for a family to meet basic needs when determining a national PFML

maximum benefit, and should ensure that the PFML maximum benefit is as close to 100 percent of the statewide average weekly wage as possible, if not higher. For an example of a policy that addresses both the issue of wage replacement and the maximum benefit, the District of Columbia’s PFML program, once implemented, will offer 90 percent wage replacement up to a threshold, and 50 percent of income above this amount for those earning above the threshold (A Better Balance, 2018a).

Wage replacement, maximum benefit, and estimated cost of living in states with PFML included in study

STATE	WAGE REPLACEMENT RATE	MAXIMUM BENEFIT (2018)	ESTIMATED COST OF LIVING FOR A FAMILY WITH ONE ADULT AND ONE CHILD (2018)*
California	60%-70% of a worker’s wages, with lower-income workers receiving a higher percentage of their average wages	\$1,216/week for both temporary disability and family leave, equal to 100% of the statewide average weekly wage	\$1,676/week in Ventura County, CA
New Jersey	66% of average weekly wages	\$637/week for both temporary disability and family leave, equal to 53% of the statewide average weekly wage	\$1,257/week in Camden County, NJ
New York	Wage replacement rate will increase each year following implementation, up to 67% in 2021	(1) \$652.96/week for family leave, equal to 50% of the statewide average weekly wage. (2) \$170/week for temporary disability	\$1,099/week in Allegany County, NY

*Counties were chosen based on reported residence of some study participants.

⁶ The Economic Policy Institute (EPI) calculates some costs based on national or state averages, using survey data that likely collected data from families that include people with disabilities. Some estimated costs are therefore likely weighed upward if those costs are generally higher for families that include people with disabilities, but EPI provides no estimates specific to families that include people with disabilities compared to families that do not. Other methodological assumptions, such as those for calculating child care costs, assume a pattern of child care inconsistent with child care needs identified by families in this study, such as child care for children over 12 years old.

5 Provide an inclusive definition of covered family.

PFML policies that do not cover care for a sibling, grandparent, grandchild, parent-in-law, stepchild, extended family or chosen family leave out many workers and families. This is especially relevant for workers in contexts where community and state supports are less accessible, and for workers who are providing support for or anticipate providing support for multiple people.

“Because of the nature of society now, we siblings find ourselves sandwiched. We have our siblings with special needs, and we need to care for them... We also see our parents aging... This is while I’m having to go back to school and build my own career. All these things are happening concurrently, and I know that even if I discover the cure for cancer, I won’t be able to economically fulfill all my responsibilities as a conscientious human being, unless there are appropriate supports that are sensitive to my situation. I’m not asking to live in a mansion in Beverly Hills, but I would like for my family and myself to thrive and have what we need to live and thrive. If policymakers were more aware of young people like me, and not just assume that because we’re young, we’re okay, that would be very helpful.”

California caregiver who provides primary support for her sister

The family members for whom workers can provide care under PFML programs vary by state. (See details in Appendix I.) In addition, as detailed above, while the FMLA defines “parent” and “son or daughter” to include workers who have an “in loco parentis” relationship (defined as “to take on the role of a parent” in DOL subregulatory guidance) with a minor child or an adult with a

mental or physical disability, gaps remain (U.S. Department of Labor Bureau of Labor Statistics, 2015). Policymakers should formulate a definition of family that explicitly encompasses more relationships beyond legal and genetic connections. In particular, restrictive definitions of family may disproportionately impact certain workers who are more likely to care for a nonrelative, including people with disabilities, the LGBTQ community, and African Americans (Robbins, Durso, Bewkes, & Schultz, 2017; AARP and the National Alliance for Caregiving, 2015). Policymakers can look to the Federal Employees Family Friendly Leave Act for an expansive definition of family (U.S. Office of Personnel Management, 1997). In this statute, a family member is defined as “any individual related by blood or affinity whose close association with the employee is the equivalent of a family relationship” (U.S. Office of Personnel Management, 1997).

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

When people apply for leave from work, they are often managing multiple stressful situations – for example, an emergency medical situation may require a hospital stay, understanding a new diagnosis, and managing a treatment plan. The anxiety can be compounded by attempting to decipher legalese or navigate complicated application processes. People in this study trusted

“I’m not asking to live in a mansion in Beverly Hills, but I would like for my family and myself to thrive and have what we need to live and thrive.”

California caregiver who provides primary support for her sister

government websites, and as such, it is crucial for government sources to be clear and accessible. Simple language on eligibility and applications, as well as a streamlined application process, can ease some of the stressors surrounding the situations that catalyze leave-taking.

A process that is easy to understand would also facilitate employers' roles in assisting people with leave requests. Employers were the primary source of information among many study participants when first attempting to learn about their leave-taking options, including federal or state leave programs. (As indicated above, employers in states with paid leave policies are able to provide their own private paid leave insurance policies, as long as the benefits of these policies are equal to or better than state policies.) This is particularly important for small businesses, many of which may not have the capacity to learn and navigate the complexities of overlapping leave policies and advise their workers appropriately.

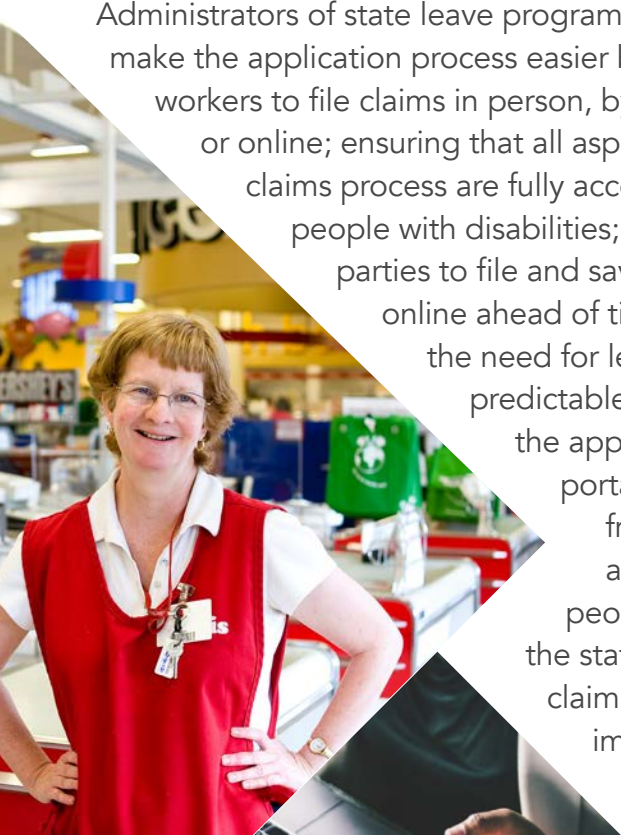
Administrators of state leave programs can make the application process easier by allowing workers to file claims in person, by phone, or online; ensuring that all aspects of the claims process are fully accessible to people with disabilities; allowing all parties to file and save claims online ahead of time (when the need for leave is predictable); making the application portal mobile friendly; allowing people to check the status of their claim online; improving help desk

capacity or toll-free hotline; offering information in additional languages; and ensuring that public information about these programs are understandable to a range of education levels and reading abilities. As a model, program administrators can look to New York's website, which was discussed favorably in a few interviews. However, while applications should be accessible online, states must also provide options for people who lack Internet access or technology fluency – a group that disproportionately includes people with disabilities (Anderson & Perrin, 2017).

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

Both workers with disabilities and caregivers are self-employed at higher rates than the general population, and workers with disabilities are more likely to be employed in government jobs (U.S. Department of Labor Bureau of Labor Statistics, 2018b; AARP and the National Alliance for Caregiving, 2015). In this study, participants who identified as self-employed worked as a food delivery or ride-share driver, consulted, or owned their own business. A high number of participants also reported being public employees, and thereby were not covered automatically under their state's paid leave programs. They may, however, have had access to paid leave if they were a part of a union and the paid leave was granted through collective bargaining agreements, which is the case for a number of California's state employees (California Department of Human Resources, 2016).

States or federal PFML programs can follow a policy of allowing public or self-employed workers to opt in to government-provided paid leave insurance policies, or alternatively a policy that ensures their participation through universal payroll deductions. Further research is needed to indicate which approach is better for providing necessary supports without unduly impacting



wages or employment. However, one of these two methods should be implemented across all paid leave programs, and in a manner that is more conducive to participation than current approaches. Both California's and New York's PFML programs allow self-employed individuals to opt-in to paid leave programs, but New Jersey's does not (A Better Balance, 2018b). New York public employees who are not currently covered under state PFML laws can opt into the program as well (New York State, 2018), but public employees in California and New Jersey are not given this option. However, self-employed workers in New York who choose to opt in must do so within 26 days of becoming self-employed, otherwise they must pay for the state's insurance policy for 2 years before they can take advantage of its benefits (New York State, 2018). In contrast, in California, a self-employed worker must pay for the state's paid leave insurance coverage for at least 6 months before becoming eligible for benefits (State of California, 2017).

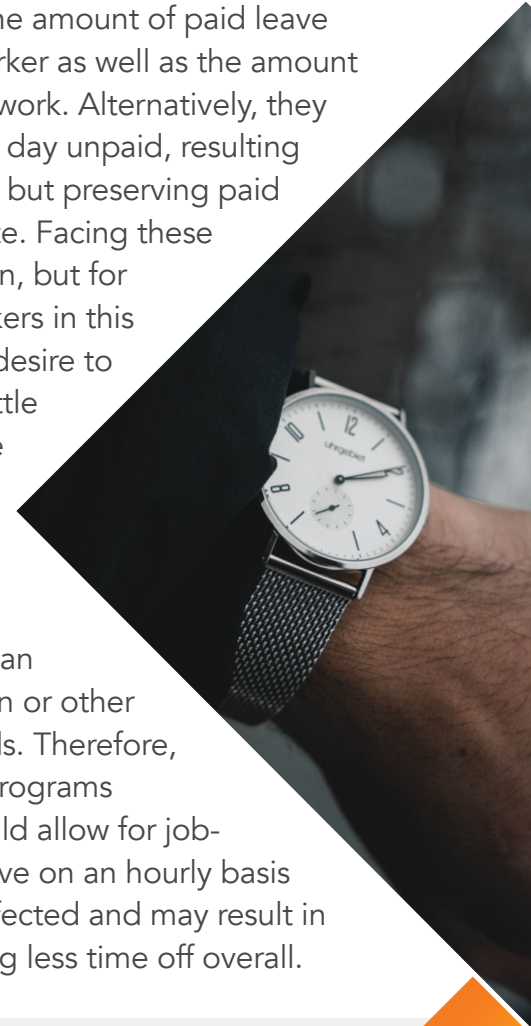
Regardless of the method of coverage, allowing self-employed and public workers coverage under PFML insurance programs in an affordable, accessible manner can provide a financial cushion during times when they are unable to earn income from working, just as it does for other workers. For example, access to paid leave could provide a consultant with supplemental income so that she can forgo taking on new clients and, instead, manage a new health diagnosis.

8 *Allow for hourly leave under all paid leave programs.*

Workers' experiences in this study revealed an important discrepancy between the FMLA and state paid family leave programs: workers covered under the FMLA can take leave in weekly, daily, or hourly increments, and while hourly intermittent leave is also allowed in California's paid family leave program (State of California, 2018), New York's and New Jersey's

family leave programs do not allow for intermittent leave lasting less than a full day at a time (New York State, 2018; New Jersey Department of Labor and Workforce Development, 2017). This means that in New York and New Jersey, workers who take unpaid FMLA leave on an hourly basis cannot get paid for those hours through their state's paid family leave programs, unless either their employer allows workers to use their employer PTO in conjunction with FMLA leave or the workers decide to take the whole day off through their state paid family leave programs.

As an example of how detrimental this misalignment can be, if a worker takes intermittent FMLA leave for a half day every week to take a loved one to medical treatments, taking a full day of New York's paid family leave for that day would use more paid family leave time than necessary, thereby reducing the amount of paid leave available to the worker as well as the amount of time they are at work. Alternatively, they could take that half day unpaid, resulting in a loss of income, but preserving paid leave for a later date. Facing these tradeoffs is common, but for the most part, workers in this study expressed a desire to be able to use as little of their FMLA leave and PFML as possible so that they can save time for when they need it the most, like for an emergency situation or other unanticipated needs. Therefore, aligning all PFML programs with the FMLA would allow for job-protected, paid leave on an hourly basis to more workers affected and may result in these workers taking less time off overall.



While a number of municipalities and states are beginning to pass paid sick day laws that are also more flexible in terms of half-days or hourly allotments, these differ from PFML programs in several important ways. For example, paid sick days legislation usually is in the form of an employer requirement rather than a social insurance program, and policies are designed to allow workers to take time off to address acute, short-term illnesses (their own or a family member's) or to secure preventive care (National Partnership for Women and Families, 2018). As a result, the amount of employer-provided sick time required (usually totaling not more than a week) is significantly less than the amount of time often needed to address health issues or disabilities of a chronic nature that may require an extended absence to address. Despite the different mechanisms and goals of PFML compared to paid sick days, policymakers can use lessons learned from the flexibility of many sick day policies as a guide in shaping more flexible PFML through intermittent and hourly use.

9 *Provide an adequate amount of leave time for workers, particularly if flexible work arrangements are not an option.* While some workers in this study were able to benefit from modest amounts of leave and many benefited from rearranging work schedules if their workplace allowed it, others expressed a need for more adequate leave amounts. This is especially relevant for workers who provide care for multiple people, are simultaneously providing support for someone and managing their own health condition, are unable to work remotely or have flexible working hours, or do not have employer-provided paid leave available to them.

"I think [FMLA] could be improved if there was more time added to it...if your spouse was experiencing cancer or something, that 12 weeks is nothing. It's a drop in the bucket."

North Carolina caregiver

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

"I use FMLA for any appointments, meetings, workshops or seminars that I go to for my son to learn more about his disability or family support."

New Jersey caregiver and worker with a disability and serious health condition

Covered leave reasons under PFML programs should be flexible enough to include meetings with special education teachers and appointments with specialists, along with other essential workshops or meetings related to education about one's disability or health condition. A small number of states provide a limited number of job-protected hours annually to eligible workers to attend school-related events and activities for their children, including California (40 hours of leave annually) and North Carolina (4 hours of leave annually) (A Better Balance, 2017). PFML programs should similarly allow for leave related to the treatment and care of a diverse array of ongoing health conditions and disabilities.

11 *Invest in outreach and education campaigns.* A number of study participants reported their fears to take leave and a desire for more empathy for their leave-taking needs. PFML legislation should include campaigns to raise awareness of the programs and reduce leave-taking stigma for all reasons. The public education campaign initiated under California's



Mental Health Services Act offers one model. Evaluations of the initiative showed a decrease in stigma against mental illness and an increase in the general public's willingness to socialize with, work with, and provide support to people experiencing mental illness (Collins, Wong, Roth, Cerully, & Marks, 2015). Similarly, a campaign that addresses the diverse needs for leave may increase support for workers needing leave from work and ameliorate fears of employer retaliation for taking leave. Outreach campaigns should be conducted in partnership with disability advocates and community-based organizations, including the following approaches:

A. Inform the public about available leave programs in multiple formats. Since many people learn and understand information in different ways, it is critical to convey information through multiple modes, like videos, flowcharts, websites, and brochures. When engaging in educational activities about leave, program administrators should conduct surveys or gather feedback whenever possible to assess whether their target audiences understand relevant information and what methods work better than others among different populations. The results of these surveys and feedback should be publicly shared, to inform policymakers and other stakeholders, and to help prioritize the most effective methods of communication.

B. Work with the disability community to ensure that communications about leave policy are inclusive. People take leave for a variety of reasons, and as such, communications should reflect these diverse needs. Communications about family leave tend to focus on bonding with a newborn, and, as seen in this study, caregivers and workers with disabilities may assume that they are not eligible as a result. Communications about leave programs should explicitly address that workers may need to care for multiple people, that caregivers may need to take time off for their own health needs, and that people with disabilities may need to use leave for not just their own health needs, but to care for others as well. Such communications should also explain the ways in which workers can use overlapping leave policies, such as how the FMLA can be used jointly with temporary disability insurance when taken for a personal medical leave, or concurrently with paid family leave when taken to care for an ill or injured family member.

C. Integrate paid leave communications with culturally competent information about disabilities. De-stigmatizing campaigns have the potential to facilitate conversations between employers and workers about requesting and accommodating leave needs. For example, an evaluation of a government-run anti-stigma communications campaign in

England found that the campaign promoted the help-seeking behaviors of people with mental illness (Henderson, Robinson, Evans-Lacko, & Thornicroft, 2017). Governments can work with groups specializing in disabilities, including disabilities that are often hidden, to design campaigns and communications that de-stigmatize such health conditions in a productive manner.

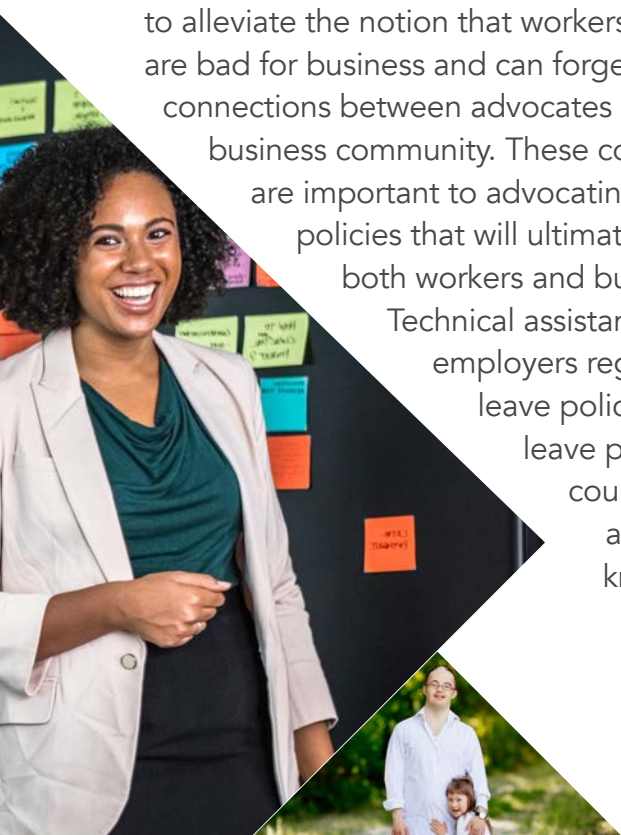
D. Conduct direct education to employers as well as workers. Messages about the value of leave-taking should be directed to employers as well as workers, especially given that many study participants reported not being properly informed by their employer about their leave options. Such messaging could highlight best practices employed by businesses to comply with unpaid leave and PFML policies as well as the business benefits for implementing such policies (Stroman et al., 2017; Lerner & Appelbaum, 2014). In particular, highlighting examples of employers who do leave well and engaging such employers can help to alleviate the notion that workers' rights are bad for business and can forge vital connections between advocates and the business community. These connections are important to advocating for leave policies that will ultimately benefit both workers and businesses.

Technical assistance to employers regarding leave policies about leave programs could also help address knowledge

gaps among employers who may be just as confused about the various leave policies as their employees.

12 *Ensure adequate resources for paid leave insurance programs.* Most states

fund their PFML programs through payroll contributions; federal policymakers are considering similar funding mechanisms for a national program. Because of the cost efficiency of this funding model, payroll contribution levels can be very modest – often less than 1 percent of pay. Adequate payroll contributions can support benefit levels that maintain economic security, fund outreach activities, and enable administrative departments to hire enough staff and invest in technical software to improve administrative efficiency. These additional costs could also be covered by raising the wage ceilings above which there are no additional payroll contributions for state PFML programs. These ceilings vary considerably: in 2018, in California, contributions for family leave insurance only apply to the first \$114,967 earned in a year; in New York, to the first \$67,908 earned in a year; and in New Jersey, to the first \$33,700 earned in a year. On the other hand, the District of Columbia is funding its paid family leave program solely through employer contributions, based on a percentage of covered employees' total wages, and, there is no ceiling on those contributions (District of Columbia Department of Employment Services, 2018). Policymakers can ensure adequate funding to support adequate benefits and strong administration by applying the payroll tax deduction to higher wage ceilings, or by removing wage ceilings entirely (Dunford, 2017).



RECOMMENDATIONS FOR EMPLOYERS

Employers may fear that managing employee leaves will be challenging and time-consuming, especially if there is no system in place already or if there is limited capacity, both of which can often be the case for small businesses. Yet, evidence has shown that facilitating employees' leave-taking can provide long-term benefits to business in terms of employee retention, morale, and profit (Stroman et al., 2017; Lerner & Appelbaum, 2014; Boushey & Glynn, 2012). In addition, employers are the gatekeepers to workers' access to leave programs. Without employer support, many workers in this study feared that their employers would interpret their need to take leave as a sign of dispensability. In contrast, many other study participants discussed several ways in which they felt supported in their caregiving responsibilities or managing their disabilities, including working with employers to ensure they were able to take adequate leave time. Such examples demonstrate that employers can foster environments that support workers' health and caregiving needs, and would reap rewards from doing so, including lower employee turnover. There are a number of resources and solutions for businesses; for example, the Employer Assistance and Resource Network on Disability Inclusion offers employers

education, online training, news, and best practices on disability inclusion in the workplace (Employer Assistance and Resource Network on Disability Inclusion, 2018).

1 *Inform all employees regularly about available leave programs in writing and in person.* While state PFML laws require that employers inform their employees about available leave programs, and the FMLA requires employers to provide a general notice to their employees about their rights under the FMLA (U.S. Department of Labor Wage and Hour Division, Employer's Guide to The Family and Medical Leave Act), it was clear that this information was not always conveyed or conveyed effectively to study participants. While employees may have been informed upon hire, people need to hear about available leave programs when they are most likely to need them (e.g., when employees divulge a medical crisis or need to leave work to care for a loved one). Further, managers, in particular, must be aware of their obligations under the law; often, workers in this study turned to their immediate supervisors about needing leave from work. Management should create a procedure for leave requests and work proactively with all staff, including human resources (if the business has such a department), to support employees' needs. Employers should clearly communicate which employees are eligible for what type of leave, and covered reasons for using leave. Effective communications can be low-cost and simple to implement. For example, information about leave

rights and eligibility can be distributed through state-issued brochures, an email with links to additional information, staff meetings, or existing employee handbooks.

2 **Implement a documented process for leave-taking.** Along with informing all employees about available leave policies and procedures, employers should have a streamlined, documented process for leave-taking. While not required under the FMLA or PFML programs, a documented process could ease confusion over how to use employer time off in conjunction with leave entitlements and PFML programs. The request for leave and subsequent responses should be in writing and dated, and all workers should be informed about the proper procedures for requesting and documenting leave time. In addition, employers should implement PTO usage policies and time off tracking systems that are accessible and understandable to workers. A documented process that applies to all workers allows those who more frequently need leave additional protection against retaliation by offering a paper trail of their leave-taking. It also allows workers to plan their leaves, when possible, in accordance with the time they have left. Employers benefit from documentation as well, as such documentation could be used to prove compliance with leave laws and provide evidence of possible employee abuse of leave policies, as well as imbuing a sense of fairness among employees that can be conducive to worker retention.

“So when I went to go back [to work after taking leave], [my employer] said, ‘We’re not letting you come back to work. We need more information. We want to talk to your doctor.’ And it was at that point I contacted an attorney. I ended up going to the hospital because of the stress...So we kept going back and forth, and we finally had to have a meeting, and I had gotten into the habit and

practice of recording my meetings, because things would be said, and nobody would write them down, and they would make promises. And then [they would say], ‘Well, that never happened.’”

New York caregiver with a disability and serious illness

3 **Allow for flexible use of employer-provided time.** Some workers want to be able to use their employer-provided leave time to address their own or a family member’s health – typically, due to individual financial needs, especially if workers are not eligible or not covered by a state PFML law. Even when eligible, many workers may prefer to use employer PTO because they find the wage replacement under their state’s paid leave insurance program inadequate. Employers’ PTO policies, including policies covering sick days, should be flexible enough to allow for time off to care for one’s own medical needs and the medical needs of family members or loved ones, and should allow for time off for preventive care or other activities related to caregiving needs, such as interviewing home health aides. Furthermore, PTO policies should allow for taking PTO without advance notice during times of crisis, which, for example, could cover a medical emergency or picking up a child from school due to behavioral issues.

4 **Allow for flexible work schedules and remote working options.** As a result of being unable to balance their health needs or the health needs of their family



members, several people in this study reported quitting inflexible jobs to change sectors, work part-time, or freelance. Many of the individuals in this study did not want to quit working. In fact, many would have preferred to continue working at their prior jobs, but with a few modifications that would have made balancing their health needs and caregiving situations a bit easier.

“If I need to take a couple of hours to drive him I can do it, then I would work late nights. Nobody would bother me. My boss doesn’t care, as long as I do my work. So that gives me flexibility, which probably many people don’t have if you are at a lower level in the organization.”

New Jersey caregiver

Working with an employee’s needs could improve employee retention, which has many benefits for employers, including keeping talented workers, fostering employee loyalty, improving performance through skill-building, lowering onboarding costs for replacement employees, and preserving institutional knowledge (Stroman et al., 2017; Danziger & Boots, 2008).

5 Implement workplace adjustments that foster an inclusive work environment.

There are many ways in which study participants did not feel supported in the workplace as a caregiver or a worker with a disability. Several study participants hesitated to talk about their need to take leave if it related to a disability. Some who cared for people with disabilities or health conditions that were not readily apparent, or who had this type of disability themselves, felt they received less empathy in the workplace. Although it is not clear whether such statements were indeed accurate, the disclosure

of such feelings reflects an overall lack of support that these workers felt. Several study participants who had or were caring for someone with multiple sclerosis, cyclical depression, and autism expressed such sentiments.

“The employees who have physical disabilities are treated better [than those that] don’t have one you can see.”

California caregiver with a serious health condition

Participants also expressed desired changes to make their workplace more supportive, such as increased empathy and understanding for their health condition or the health condition of the person for whom they provide support. The following suggestions for fostering empathy in the workplace are low-cost and may have business benefits as well in terms of employee loyalty, retention, and morale.

- A. Sensitivity and educational trainings on caregiving and disability with all management levels:** Study participants felt that managers or co-workers who knew someone with a disability or a health condition necessitating leave were particularly supportive. A meta-analysis of interventions that bring people directly in contact with people affected by mental illness found them to improve attitudes and behavioral intentions toward people with mental illness (Corrigan, Morris, Michaels, Rafacz, & Rusch, 2012). One study participant suggested that partnering with local disability groups, like centers for independent living, and having people with disabilities speak at workplaces could enhance empathy for people with disabilities and caregiving responsibilities.

“Currently and in the past, all the people that I work with have some sort of disability even then if it’s acquired, visible, or invisible. I think...even people without disabilities can come in too, so [it’s] a welcoming, a special community.”

North Carolina worker with cerebral palsy

“I think the first step [to increase compassion in the workplace] is just to talk about it period. So just talking about it with peers and at work, which is why I was also more open about disclosing it to some coworkers and my employer. You have to talk about it to destigmatize it.”

New York worker with mental illness

Institute’s survey on disabilities in the workplace, people with disabilities who have a mentor report more positive workplace experiences, making them more likely to feel like their company is inclusive and to recommend their employer to others (Working Mother Research Institute, 2016).

“My mentor has been very helpful to me [for] how to address [the disability] in an interview, to address what effect it has on me and ways it might be useful or an area of strength. At the very least diffusing some tension by me bringing [the disability] up. We rehearsed that a lot, I brought it up during the interview and it was very effective.”

New York caregiver with a disability

B. Mentors: Pairing new hires with a mentor can greatly enhance an employee’s experience at work. In the Working Mother Research



RECOMMENDATIONS FOR ADVOCATES

Many people in this study had not heard of unpaid or paid family and medical leave programs. Community-based organizations, including service providers and advocacy groups, serve an important role in outreach and education, as families trust information from these groups. Below are several recommendations for how advocacy organizations can amplify government outreach efforts to inform the public about the availability of leave programs. These recommendations are informed by the sources of information that participants indicated they trusted and used to attain information about leave programs. In particular, study participants reported that they trust information from others who have had personal experience navigating through a similar situation as their own. People also expressed trust in online peer forums, health care providers, support groups, government websites, and service organizations.

1 Conduct outreach to health care providers. When people need to take leave due to a health crisis, they are often overwhelmed with information. Health care workers, like doctors, nurses, and hospital social workers, are trusted sources of information for many during a health emergency, and since they

are likely to be interacting with many people as they learn that they need to take leave from work, information about leave rights and state leave programs is more likely to be understood when delivered at the time when it is most applicable. A Better Balance's October 2018 report, *For the Health of Our Families*, offers multiple ways advocates can engage the medical community to integrate information about leave programs during health care encounters (A Better Balance, 2018b).

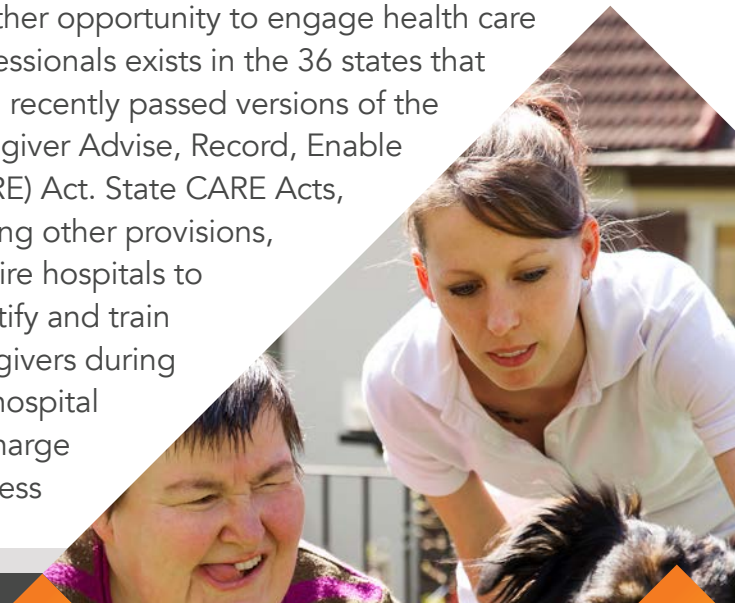
“Even the treating doctors and facilities – they could have some information about [leave programs]. The medical facilities, and of course the social worker...I was taking my son to a private hospital and the social worker should have had this information.”

New York worker caring for a son with mental illness

“We’ve got a social worker [at the hospital] who supposedly knows the system, knows what kind of support stuff is out there, and never once did the social worker give me any information, you know, a list of websites or a brochure.”

California caregiver

Another opportunity to engage health care professionals exists in the 36 states that have recently passed versions of the Caregiver Advise, Record, Enable (CARE) Act. State CARE Acts, among other provisions, require hospitals to identify and train caregivers during the hospital discharge process



(AARP, 2014). Advocates can reach out to hospitals to ensure that education on the FMLA and paid leave is folded into required education and training for caregivers to further alleviate the stressors of caregiving.

2 Use online communities for outreach and education.

A number of study participants reported obtaining valuable information from Facebook groups or other online forums whose members include others affected by a shared disability or health condition.

“Many times [other parents will] go to message boards where people are discussing their experiences, like real life people discussing their experiences with these different agencies and sometimes I can glean some information from them, not hard truths, but at least, get some angles that I didn’t think of or that weren’t presented on the Social Security website or the Medicaid website.”

New Jersey caregiver

Study participants largely trusted advice and information from others who were facing similar situations and challenges. Advocacy groups should consider creating an online group on popular platforms like Facebook⁷ to educate people about leave rights and programs and provide a forum for discussing questions, concerns, and experiences on leave. One example is the Facebook page of NJ Families for Paid Leave (found at <https://www.facebook.com/groups/NJFamiliesforPaidLeave/>), run by the New Jersey Time to Care Coalition. Investing in social

media ads to spread awareness and accurate information of a program could be an additional strategy.

“I belong to some Facebook groups where parents try to support each other, but some of those parents are speaking not from a position of knowledge. So parent-to-parent support is very powerful and allows people to seek that out, but it’s important to make sure that the person providing you information in parent-to-parent support knows what they’re talking about. I would say reaching out to parent groups and providing information to those groups that is correct so that it can be shared with other parents.”

California caregiver

3 Coordinate with service and advocacy organizations.

Participants listed multiple organizations they turn to when they want more information about a certain health condition or disability.⁸ Paid leave advocates can reach out to these organizations so that they can provide and direct people to more information about leave programs.

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

These organizations have consistent access to populations that provide support to people with health conditions and disabilities. Disseminating information to health insurers will also increase the resources that these organizations can provide for clients and their families.

⁷ Other online platforms mentioned included Reddit and Tumblr, but participants most commonly cited Facebook groups as sources of helpful information.

⁸ Organizations mentioned by participants included National Alliance on Mental Illness, local YMCAs, independent living centers, the National Multiple Sclerosis Society, Alzheimer’s Research Association, the Down Syndrome Network, Special Olympics, and the Sibling Leadership Network.

DISCUSSION

States are often referred to as laboratories for policy experimentation. Evidence from such policy experiments lend valuable insights not only for other states looking to implement parallel policies, but also for the potential to scale policy to the national level. The recommendations

in this report can provide a roadmap for structuring a state paid leave program, but the formation of a national paid leave program would consistently address many of the barriers experienced by people in this study. Much of the confusion on state leave programs as well as the administrative burden of leave policies on both workers and employers would be alleviated by the implementation of a single, baseline national paid leave program. Moreover, a comprehensive, national leave program would allow access to paid leave for workers regardless of where they work. Marrying the job protection and other anti-retaliatory provisions of the FMLA with the economic security afforded by state paid leave programs would not only promote productivity, but also support the full inclusion of people with disabilities and their families in the workforce.

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APPENDIX I: PRIMER ON FEDERAL AND STATE LEAVE PROTECTIONS AND PROGRAMS

FEDERAL LEAVE PROTECTIONS

The Family and Medical Leave Act of 1993 (FMLA) is a landmark law for leave protections in the U.S. While the FMLA has become nearly synonymous with maternity or paternity leave over the years, the law covers more than just parents of newborns. It also provides critical job protection for workers to take time off to address their own serious health conditions or to care for a family member with a serious health condition. Eligible workers can take up to 12 weeks of job-protected FMLA leave in a 12-month period if they have worked 1,250 hours in the 12 months prior to taking leave, and work for a covered employer with 50 or more employees in a 75-mile radius for at least a year. The FMLA covers 59 percent of the workforce (Klerman, et al., 2012). Protections under the FMLA include protection against discrimination or retaliation, employer interference, or being discharged for exercising any FMLA right (U.S. Department of Labor Wage and Hour Division, 2011).

The Americans with Disabilities Act of 1990 (ADA) is a landmark civil rights law prohibiting discrimination against people with disabilities and ensuring equal opportunity for people with disabilities to participate fully in all aspects of community life. Among its many provisions, the ADA allows covered workers with disabilities to request reasonable accommodations on the job related to their disability. Workers are eligible for protection under the ADA if they have an ADA-covered disability and they work for a company with 15 or more employees (U.S. Equal Employment Opportunity Commission, 2018). ADA-covered workers may request unpaid leave as a reasonable accommodation, even if they have used all of their FMLA leave or if they are otherwise ineligible for leave under FMLA (U.S. Equal Employment Opportunity Commission, 2016). At this time, little is known about how often workers request unpaid leave as a reasonable accommodation under the ADA or how many workers are aware that the ADA also enables workers to take leave when needed.

STATE PAID LEAVE PROGRAMS

In recognition that workers face financial barriers to taking unpaid leave, several states have passed their own paid family and medical leave policies. As of December 2018, five states currently administer their own temporary or short-term disability insurance programs which allow eligible workers to take partially paid time off work to address their own non-work-related injury or health condition. Four of those states -- California, New Jersey, Rhode Island, and New York -- have expanded these longstanding temporary disability programs so that workers can receive a portion of their paycheck when they need to take leave to care for a family member, also known as paid family leave. Hawaii, whose temporary disability program operates through a requirement that employers provide temporary disability insurance rather than through a state-regulated public insurance program like the other states, is the only state with a temporary disability program that does not yet have a paid family leave program. In addition, the District of Columbia, Washington state, and Massachusetts have passed legislation to offer paid family and medical leave through the state as well, with leave benefits to be available in 2020 (D.C. and Washington state) and 2021 (Massachusetts). Moreover, a number of bills have been introduced in other states to study or to implement PFML.

Each state's paid leave program varies in terms of their wage replacement (ranging from 50 to 90 percent of average weekly wages), covered reasons for taking leave under the program, length of leave allowed, the definition of family covered for family caregiving, whether job protection is afforded, and who is eligible. More information about state variations in paid leave is available from a website maintained by A Better Balance at <https://www.abetterbalance.org/resources/paid-family-leave-laws-chart/> and from a National Partnership for Women & Families website at <http://www.nationalpartnership.org/research-library/work-family/paid-leave/state-paid-family-leave-laws.pdf>.

JOB PROTECTION AND THE INTERACTION OF FMLA AND STATE LEAVE PROGRAMS

In New York, paid family leave is job protected while paid medical leave through the temporary disability program is not job protected; the same is true in Rhode Island. In California and New Jersey, neither the state paid family leave programs nor temporary disability insurance programs are job protected. North Carolina workers in the private sector are only protected by the FMLA and ADA (for workers with disabilities), and only have access to whatever paid leave their employers provide, as North Carolina has no state-level protections or state paid leave program.

If workers are eligible for FMLA and take paid leave through a state program, they must count their paid leave time toward FMLA simultaneously, if taken for the same reason. For example, a worker who lives in CA or NJ and takes 6 weeks of temporary disability insurance leave for a broken leg will see their FMLA time run concurrently with those 6 weeks. At the end of that time, the worker will still have 6 weeks of FMLA left in the year. If the same worker later needs to care for a child in that same 12-month period, the worker can take the state's paid family leave program alongside FMLA, for both partially paid leave and job protection, but will be limited to 6 weeks of FMLA coverage.

FAMILY DEFINITION

In California, workers can take leave to provide support for their child, parent, grandparent, grandchild, sibling, spouse, registered domestic partner, or the parent of a worker's spouse or registered domestic partner. In New York, workers can take leave to provide care for all of these, but not a sibling; in addition, the definition of domestic partner is flexible and does not require registration. New Jersey's program has the most restrictive definition of family member, covering only workers who need to care for their child, parent, spouse, registered domestic partner, or civil union partner. In the FMLA, family is defined as a spouse, son, daughter, or parent. The definition of a son or daughter includes individuals for whom a worker is "in loco parentis", Latin for "in the place of a parent" to indicate similarity to a parent-child relationship. The definition of a parent includes those who stood "in loco parentis" to the worker when the worker was a child (U.S. Department of Labor Wage and Hour Division, 2015).

APPENDIX II: DETAILED METHODS AND SAMPLE STATISTICS

DETAILED METHODS

The research team jointly developed a codebook containing themes related to key research questions and coded each transcript accordingly using ATLAS.ti 8 analytic software. Researchers grouped codes into categories relevant to the research questions and further analyzed code relationships through a data display. Columbia University Medical Center’s Institutional Review Board approved all study procedures. The states included in the study were selected to represent a range of policy contexts. California, New Jersey, and New York all offer their own state PFML insurance programs, while North Carolina does not. These three states run their own temporary disability insurance programs for medical leave and paid family leave programs for leave to care for a family member so that workers can receive a portion of their pay during their leave. Benefits are funded primarily through workers’ payroll contributions, although in New Jersey and New York, state disability benefits are funded jointly through employer and employee contributions. These first three states with PFML have policy variations that can impact leave-taking patterns – for example, all three states have different wage replacements rates. They also vary in terms of the percent of a worker’s wages provided during leave, the length of leave provided, and the definition of a family member for family leave, among other variations. They also differ in terms of administration of benefits, whether they allow employers to self-insure or use a private insurance option for TDI, PFL or both, and application processes. *See Appendix I: Primer on Federal and State Leave Programs, for more details about federal and state leave policies.*

SAMPLE CHARACTERISTICS

State of work

State	# of participants	% of total participants
NJ	23	25.56%
CA	19	21.11%
NC	24	26.67%
NY	24	26.67%
Total	90	100.00%

By disability and support status

% of total participants providing support only	50%
% of total participants with serious health condition and/or disability	50%
% of total participants who had a serious health condition and/or disability and also provided support	38%

Reasons for taking leave for more than a “few” days

Leave-taking reason	# of participants	% of total participants
For own health	23	25.56%
For caregiving purposes	56	62.22%
For both caregiving and own health	15	16.67%
For either caregiving or own health (total who took leave for more than a few days)	64	71.11%

Ages

Age range	# of participants	% of total participants
25-34	12	13.33%
35-44	20	22.22%
45-54	25	27.78%
55-64	22	24.44%
>65	9	10.00%
Not available	2	2.22%
Total	90	100.00%

Gender

Male	Female	Other	Total
11	78	1	90
12.22%	86.67%	1.11%	100.00%

Race/Ethnicity

Ethnicity	# of participants	% of total participants
White (Non-Hispanic)	63	70.00%
Black	11	12.22%
Mixed	4	4.44%
Asian	1	1.11%
White Hispanic	4	4.44%
Hispanic	5	5.56%
Native	1	1.11%
Not available	1	1.11%
Total	90	100.00%

Country of Origin

U.S. born	Not born in U.S.
82	8

Marital Status

Marital Status	# of participants	% of total participants
Married	53	58.89%
Married, living separate	1	1.11%
Single	22	24.44%
Living with a partner	1	1.11%
Divorced	10	11.11%
Widowed	3	3.33%
Total	90	100.00%

Sexual Orientation

Orientation	# of participants	% of total participants
Straight/Hetero	78	86.67%
Gay/Lesbian/Bisexual	8	8.89%
Other	2	2.22%
Not available	2	2.22%
Total	90	100.00%

Workplace sector and changes in job or job status

(This includes previous jobs as well as current jobs – and multiple jobs – per interviewee.)

Workplace characteristics	# of participants	% of total participants	# of participants who had a disability/serious health condition	# of participants who were a caregiver
Currently or previously public sector employee (government employee, including public school employees)	26	28.89%	12	24
Currently or previously self-employed	11	12.22%	7	10
Currently or previously private sector or nonprofit employee	60	66.67%	31	51
Left at least one job at some point in career due to inability to take leave, lack of employer support, or insufficient accommodations	18	20.00%	12	15
Changed job status (includes going part-time, going freelance, and moving from one full-time job to splitting employment between part-time and freelance)	19	21.11%	13	14

Breakdown of current or most recent job
(For people currently with two jobs, industry represents primary job)

Workplace characteristics	# of participants	% of total participants
Currently or most recently a public sector employee	20	22.22%
Currently or most recently self-employed	10	11.11%
Currently or most recently a private sector or nonprofit employee	53	58.89%
Industry sector for current or most recent job not identifiable	7	7.78%
Total	90	100.00%

Work status

	# of participants	% of total participants
Full-time	63	70.00%
Part-time	27	30.00%
Total	90	100.00%

Relationship to person receiving care

Person receiving care		# of participants	% of total participants
Child	Minor child or children (under 18 years old)	28	31.11%
	Adult child or children (18 years or older)	23	25.56%
Participants caring for at least one child (minor or adult)*		49	54.44%
Spouse		9	10.00%
Sibling		9	10.00%
Parent(s)		15	16.67%
Nephew/Niece		1	1.11%
Grandchild		4	4.44%
Grandparent(s)		1	1.11%
Friend		4	4.44%
Other relationship		2	2.22%
Participants providing care to 2 people		9	10.00%
Participants providing care to 3 or more people		10	11.11%
Sandwich (caring for a child and parent/parents)		4	4.44%
Participants caring for 2 or more people		19	21.11%
Participants caring for someone not explicitly covered under FMLA**		21	23.33%

*Note: The reason why the number of study participants caring for at least one child is lower than the total of participants caring for minors and adult children is due to cases in which participants reported caring for both adult children and minor children.

**This number includes possible "in loco parentis" relationships. See Appendix I for more information.

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.

State median income by household size

(American Community Survey 2012-2016, 5-year estimates, Table B19019)

Household size	NY median income	NJ median income	NC median income	CA median income
1-person households	\$31,631	\$34,857	\$26,376	\$34,788
2-person households	\$67,837	\$78,051	\$55,593	\$71,370
3-person households	\$78,014	\$94,309	\$61,907	\$76,470
4-person households	\$91,534	\$111,966	\$71,232	\$84,135
5-person households	\$86,737	\$105,861	\$63,281	\$72,436
6-person households	\$81,849	\$104,151	\$57,810	\$71,358
7 or more person households	\$84,537	\$95,260	\$59,760	\$80,358

Number of participants who took up state’s paid family leave programs

Note: Paid family leave (PFL) is only available to caregivers, and is separate from medical leave to care for one’s on disability.

	Never took PFL	Took PFL for either bonding or caregiving	Took PFL for bonding	Took PFL for caregiving	Took PFL for both bonding and caregiving, separately
Caregivers living in a state with PFL and who had jobs outside of the public sector	40	10	5	5	0

Breakdown of reasons why participants in sample were not eligible for PFL

	# ineligible for PFL
Non-caregivers in sample	10
Caregivers living in a state without PFL	20
Caregivers living in state with PFL but who worked solely in the public sector	10

Health conditions and disabilities in sample, by category. Vague terms and additional descriptions provided by interviewees are in quotes.

Intellectual and/or Developmental Disability (IDD)	attention-deficit/hyperactivity disorder, autism spectrum disorder (including Asperger’s syndrome), Batten disease, cerebral palsy, Down syndrome, dysgraphia, dyslexia, Ehlers-Danlos syndrome, hydrocephaly, intellectual disability, leukodystrophy, mosaic trisomy-9, SATB2-associated syndrome, spina bifida, Tourette syndrome, “developmental disabilities,” “learning disability,” “learning disorders”
Neurological conditions, other than IDD	carpal tunnel syndrome, cervical radiculopathy, epilepsy, essential tremor, migraines, multiple sclerosis, myoclonus, neuropathy, radiculopathy, seizures, spinal muscular atrophy, traumatic brain injury, transient ischemic attacks
Physical conditions, other than IDD or neurological condition	amputated leg, ankylosing spondylitis, arthritis, asthma, brain aneurysm, brain tumor, cancer, cannot walk, chronic pain, chronic obstructive pulmonary disease, Crohn’s disease, cyclical fever syndrome, diabetes, Epstein-Barr virus, fibromyalgia, gastritis, high cholesterol, hypertension, inflammatory bowel disease, irritable bowel syndrome, leukemia, lupus, Lyme disease, lymphedema, mobility issues, muscle weakness, muscular atrophy, myalgic encephalomyelitis (chronic fatigue syndrome), on ventilator, uses a tracheostomy tube, osteoarthritis, psoriatic arthritis, punctured lung, reactive arthritis, rheumatoid arthritis, stroke, temporomandibular joints (TMJ) disorders, ulcerative colitis, urological issues resulting from loss of bladder, “autoimmune disorder,” “back issues,” “can’t eliminate properly,” “can’t swallow well,” “chronic heart problem,” “chronic respiratory issues,” “clotting disorder,” “congenital hip condition,” “connective tissue disorder,” “constant pain,” “gastrointestinal issues,” “joint issues,” “mobility issues,” “musculoskeletal issues,” “rare kidney disease,” “thyroid issues,” “transgender-related health conditions,” “walks with crutches”
Mental illness, other than memory issues	anxiety, bipolar disorder, depression, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder, schizophrenia, “behavioral issues,” “emotional issues,” “mental health issues,” “mood disorders”
Memory issues	Alzheimer’s disease, dementia, myoclonic impairment, memory issues
Vision impairments	blind, keratoconus, legally blind, macular degeneration
Other or unclear	unclear, “alcoholism,” “elderly and having health crisis,” “elderly,” “executive dysfunction,” “other complex medical needs,” “very young”

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.



