

Understanding Working & Caregiving

An Analysis of California's Paid Family Leave



CALIFORNIA
Work & Family
COALITION

October 2018
HumanImpact.org

Executive Summary

“... for me it's something that fills my heart, knowing that he needed every one of us and it was about making sure he didn't feel alone during that time.”

-Rosa, caregiver to a grandparent with a terminal illness

We all want to be there for our loved ones in their time of need — to give love and care. Being a caregiver can look vastly different for each of us, whether it's welcoming a new child as parents, taking care of a parent as they age, or making sure a best friend is managing a chronic health issue safely and well. We shouldn't have to compromise our own health or wealth to provide love and care — yet many of California's family caregivers are forced to make this choice.

Family caregivers — that is, those who provide care for a loved one with a serious health condition — play immensely important and also exhausting roles. Most of us who are in a caregiving role have one or more jobs, which we need to make ends meet. Juggling the priorities of caring for a loved one and working is a lot to handle. The energy it takes to be a caregiver is really a job unto itself.

Caring for our family and friends in their time of need is one of our biggest priorities.

In this report, we explored the ways in which paid family leave policies in California fall short of supporting all working caregivers, the role of workplace policies to support their employees in fulfilling their caregiving needs, and what people who care for loved ones while working experience as a result of current public and workplace policies. We designed our research efforts to inform policymakers, advocates, policy administrators, and employers on ways they can better meet the needs of people in caregiving roles.

California's Paid Family Leave (PFL) Is an Attempt to Support Working Caregivers

California's Paid Family Leave (PFL) provides up to six weeks of partial pay to eligible workers who take time off work to care for a new child or seriously ill family member. PFL is funded entirely by workers whose payroll taxes contribute to the State Disability Insurance program (SDI), administered by the Employment Development Department (EDD). That is, PFL is not a government subsidy.

Yet PFL Doesn't Support Everyone

Although approximately 18.1 million California workers are covered by PFL, many aren't: contractors, the self-employed, and many public sector employees are left out of eligibility. Many aren't made aware that PFL is a benefit they pay into — with people of color, immigrants, and those working in low-wage jobs most impacted by this. Even if they learn about PFL, people in caregiving roles opt not to use the benefit for many reasons: insufficient

wage replacement, lack of job protection, and confusion or hassles with the application process, to name a few examples.

Some Caregivers Have Access to Other Workplace Supports

Working family caregivers resort to other workplace supports like schedule changes and paid time off instead of PFL. However, these supports aren't widely available. We found that those who rely on every cent of their paycheck to make ends meet suffer the most from not being able to take advantage of PFL, despite paying into the program. And these caregivers usually don't have the necessary support from their employers to care for their loved ones, through scheduling changes or other accommodations.

Ways to Ensure All Caregivers Can Use Paid Leave and Workplace Supports

To improve the quality of life for working family caregivers, workplace policies and practices — like PFL — must consider the context of our lives. We conclude this report with recommendations for supporting California's working family caregivers as they work and tend to their loved ones.

These recommendations ask policymakers, PFL administrators, employers, and advocates to serve the caregiving community with as much devotion as caregivers use to tend to their loved ones.

- **Policymakers:** enhance family leave policies, like PFL, to see that they serve every caregiver and are realistic of caregivers' situations. Policymakers should also set better standards for good jobs, through livable wages, health and retirement benefits, to promote financial stability and good health of caregivers.
- **Government agencies, like the EDD:** ensure that the policies and programs they implement are accessible and equitable and that caregivers do not experience barriers in learning about them or using them.
- **Employers:** support caregivers so that caregiving is feasible, and create good jobs — those that provide time off, schedule flexibility, livable wages, and benefits.
- **Advocacy organizations:** address the social and emotional needs of working caregivers and increase opportunities for social support and training, with funding support.

More often than not, all of us will find ourselves in a position to provide care to a loved one. Making family leave policies accessible, comprehensive, and equitable for all Californians is the right thing to do and benefits everyone.



Sisters, working together to provide love and care for their elderly mother

Authors and Acknowledgments

Authored By

Sukhdip Purewal Boparai, MPH
Jonathan Heller, PhD

In partnership with Jenya Cassidy and Melisa Acoba, California Work & Family Coalition, and with support from Casey Adams Jones, Martha Ockenfels-Martinez, Sara Satinsky, and Ana Tellez, Human Impact Partners.

Suggested Citation

Human Impact Partners and California Work & Family Coalition. October 2018. Understanding Working and Caregiving: An Analysis of California's Paid Family Leave. Oakland, CA.

Contact Information

Jonathan Heller
Human Impact Partners
jch@humanimpact.org
www.humanimpact.org
510-452-9442, ext.100

Acknowledgments

We extend gratitude to the hundreds of working family caregivers across California who shared their stories. We also thank many people and organizations who supported this project in different ways.

Project advising team:

Donna Benton, University of Southern California Family Caregiver Support Center/LACRC; Nina Weiler-Harwell, AARP of California; Kathy Kelly, Family Caregiver Alliance; Dr. Curtis Chan, and Jenna Gaarde, San Francisco Department of Public Health, Maternal, Child & Adolescent Health; Jenna Gerry, Sharon Terman, and Katie Wutchiett, Legal Aid at Work; Laura Eberly, YWCA San Francisco & Marin.

Support with recruitment and data collection:

Nelson Motto and Natasha Castro, Los Angeles Alliance for a New Economy; Manuel Villanueva, Restaurant Opportunities Center of Los Angeles; Samuel Molina and Giselle Gazca, Mi Familia Vota; Alice Berliner, Southern California Coalition for Occupational Safety & Health; Amy Fish, Agency on Aging Area 4; April Villafaña, North County Advocacy; Arissa Palmer, BreastfeedLA; Women's Foundation of California; Equal Rights Advocates; Nancy Murish,

Congress of California Seniors; California Child Care Resource and Referral Network; Caring Together Lompoc; AARP California; Alzheimer's Association; Alzheimer's Greater Los Angeles; California Task Force on Family Caregiving; Trish Hughes Kreis, Writer/Caregiver; Marc Victoria, Orange County Civic Engagement Table; Jessica Bartholow, Western Center on Law and Policy; Parent Voices; Sarah Leadem, California Domestic Workers Coalition; Child Care Law Center; Denise Tugade, Office of Assemblymember Lorena Gonzalez Fletcher; Lisa Gardiner, Office of Senator Hannah Beth Jackson; Barbara Finch, Santa Barbara County Department of Social Services; Brady Oppenheim, Coalition for Compassionate Care of California; Eliza Blum, Organization United for Respect at Walmart (OUR Walmart); Flor Rodriguez, CLEAN Carwash Worker Center; Grace Avila, USC Family Caregiver Support Center; Julia Frudden, Child Care Law Center; Julia Wackenheim, Caring Across Generations; Katie Waters-Smith, BreastfeedLA; Khammany Mathavongsy, Rise Together Bay Area; Krista Niemczyk, California Partnership to End Domestic Violence; Lisa Schoyer, Los Angeles County Department of Mental Health; Lindsay Imai Hong, Hand in Hand; Sarah Jarmon, Senior and Disability Action; Miguel Paredes, St. John's Well Child & Family Center; Maya Paley, National Council of Jewish Women/LA; Pip Marks, Family Voices of California; Renata Moreira, Our Family Coalition; Robbie Gonzalez-Dow, California Breastfeeding Coalition; Talia Stender, City of Berkeley, Office of Councilmember Ben Bartlett; Aditi Fruitwala, ACLU of Southern California; Betsy Butler, California Women's Law Center; Ana I. Grande, Mount Saint Mary's University; Patti Prunhuber, Child Care Law Center; Yeri Shon, HIP.

About the California Work & Family Coalition

The California Work & Family Coalition (CWFC) is an alliance of community organizations, unions, nonprofits, and individuals dedicated to helping parents, caregivers, and families thrive. The Coalition's mission is to organize communities to realize equitable, family-friendly workplaces and to expand the social safety net in California through policy, advocacy, and education.

About Human Impact Partners

Human Impact Partners (HIP) brings the power of public health to campaigns and movements for a just society through research, advocacy, capacity building, and field building. Our mission is to transform the policies and places people need to live healthy lives by increasing the consideration of health and equity in decision-making.

We thank The California Wellness Foundation and The California Endowment for their generous financial support for this project.

Table of Contents

Executive Summary	2
Authors and Acknowledgments	4
Introduction	7
About this report	9
Workplace policies: what are they and who do they benefit?	10
Family leave policies are not equitable	11
California’s Paid Family Leave Falls Short	14
Over two thirds of working caregivers don’t understand PFL	14
Barriers to participate in PFL are worse for low-wage workers	15
Recommendations to ensure that PFL works for everyone	18
Workplace Supports Help Some Out	22
Caregivers are using other workplace supports instead	22
But not everyone has workplace supports	24
Recommendations to improve access to workplace supports	26
Beyond Policies and Workplace Supports	27
Caregiving for a loved one is a challenging undertaking	27
Caregiving for a loved one is a social benefit	28
Recommendations to protect the well-being of caregivers	29
Conclusions and Recommendations	32
A call to improve conditions for California’s working caregivers	32
References	34
Appendices Overview	37
Appendix A: Key informant interview tool with a summary of findings	38
Appendix B: Working family caregiver survey tool with a summary of findings	48
Appendix C: Focus group tool with summary of findings	63
Appendix D: Caregiver interview tool with summary of findings	68

Introduction

“A caregiver in our situation is an advocate for my son. I take it very seriously, and I know that his life literally depends on it.”

- Stacey, caregiver to son with chronic illness

At some point in our lives, we are all *caregivers*. That is, we all choose to dedicate our time and energy to care for someone we love. Making a meal, picking up a prescription, or providing emotional support during a trying time is the day-to-day way we show up for our partners, our parents, our children, and countless other loved ones — whether they’re biological or chosen family.

Caregivers call themselves by many names. Some identify their role through their relationship, e.g., “being a good daughter,” and others by the duties or tasks they perform, e.g., “taking my dad to appointments and cooking his meals.”

Being present for those we call family during challenging times is what makes our relationships real and life meaningful. However, workplace and resource constraints can make it very difficult to do that. Over 4.5 million unpaid and informal caregivers in California face a daily uphill struggle to balance work and be present for their loved ones.¹

Caregivers experience poor mental and physical health

Even though caregiving can be a rewarding role, about 1 in 4 of caregivers report their own health to be fair or poor.² Caregivers experience high levels of stress, depression, social isolation, and poor mental and physical health.^{3,4} People in caregiving roles often develop these outcomes from neglecting their own needs, especially working caregivers who juggle multiple priorities.

“I’m not my best self. I’m short tempered, I’ve gained weight, I’m not eating healthy, I’m not getting the sleep that I need.”

- Soraya, caregiver to mother with terminal illness

Caregivers — many of them women — also experience financial strain

Most caregivers work either part-time or full-time and report needing to cut their hours to accommodate caring needs.⁵ Caregivers also quit or retire prematurely, therefore compromising access to stable income, healthcare benefits, retirement plans, and Social Security.⁶ Doing so often means that they can’t make ends meet — they can’t afford housing, food, energy bills, or other necessities.

Women, who are more likely to take on caregiving roles, and who make disproportionately lower wages to begin with, are more likely to leave the workforce to care, and more likely to enter poverty as a result of caregiving responsibilities.⁷

Caregiving itself can be costly — family caregivers spend \$7,000 a year on average on caregiving costs, almost 20% of their income. Low-income, and Black and Latinx* caregivers will spend a greater proportion of their earnings on caregiving — as much as 40%.⁸

While caregivers' financial situations become more taxing, the state actually benefits tremendously from the cost savings to social programs and assisted living through the role that caregivers play.⁹

Working Family Caregivers Represent All Kinds of Identities



*"I live with my partner, but I don't have children, so it's assumed that I would be available to take care of them [my parents]. I don't mind, but there are times you just get burnt out. And there's a difference [in the emotional support] I receive ... **As a gay man, you learn to take care of yourself.**"*

– Tony



"Friends and coworkers make assumptions that because I'm Asian, I'm obligated to do this [caregiving]. This framing is damaging. It makes me feel powerless. I'm not doing it because I have to. It really is a personal choice. I really want to do it."

– Alice



"Being an older worker, taking time off [by using PFL] may actually work against you. If you're a low-income, older worker... you might be easier to replace."

– Mary



"It's a very stressful thing to be a parent of a chronically ill child. I'm the gatekeeper and monitor of his vitals like, bowel movements, coughing, and temperature. If anything changes, I'm the one that needs to change course and figure out the next step."

– Stacey

* "Latinx" is an inclusive, gender neutral label for Latino/Latina

About this report

Working family caregivers experience significant burdens in their dual roles as workers and caregivers. Workplace policies and our work environments should do a better job at accommodating caregivers' needs and priorities.

In response to these concerns and the need to understand holistic and equitable solutions that benefit all working family caregivers, the California Work & Family Coalition and Human Impact Partners collaboratively designed and implemented a research project to understand the needs of working family caregivers and their awareness and utilization of, and access to California Paid Family Leave and other workplace supports.

For the project, the team collected data using the following methods:

1. Literature reviews of PFL and other workplace policies and supports (like Paid Sick Leave)
2. Interviews with stakeholders who work with family caregivers and employers. These stakeholders represented organizations such as nonprofits, advocacy groups, and government agencies
3. Statewide survey targeting working family caregivers inquiring about experiences of working and caregiving
4. Focus groups with working family caregivers, including Spanish speakers working in the retail/service industry
5. Interviews with caregivers from unique backgrounds or care situations, including those who identify as Asian or Pacific Islander (API), lesbian, gay, bisexual, transgender, or queer (LGBTQ), older worker, caring for a chronically ill child, or used PFL

Lessons from the project will inform campaign efforts to inform policy solutions that will support the capacity of California's current and future workforce to be able to care for the people who matter most to them.



A caregiver helps his aging father celebrate his birthday with a slice of cake

Workplace policies: what are they and who do they benefit?

Depending on where people work, those who play a caregiver role for a loved one may have state and federal resources that they could tap into for financial support.¹⁰⁻¹² These workplace supports could alleviate the stress of negotiating time off of work by allowing caregivers to take leave to assist a family member with a serious health condition.

The eligibility requirements and benefits vary among these policies, as the table details.

Table 1. Workplace family leave policies available to California’s working caregivers

Policy	Length of Leave Allowed / Eligible Work Places	Benefits during leave			Other eligibility information
		Payment	Job Protection	Health benefits	
CFRA California Family Rights Act, 1992	12 weeks in places with 50+ employees	X	✓	✓	<ul style="list-style-type: none"> - Must be employed at least 12 months with 1,250+ hours worked with current employer - Documented need of care for parent, child, spouse, or registered domestic partner
FMLA Federal Family and Medical Leave Act, 1993	12 weeks in places with 50+ employees	X	✓	✓	<ul style="list-style-type: none"> - Must be employed at least 12 months with 1250+ hours in 12 months with current employer - Documented need of care for parent, child, or spouse
PFL California Paid Family Leave, 2004	6 weeks (no employee size restrictions)	✓	X	X	<ul style="list-style-type: none"> - Must have accrued \$300+ in State Disability Insurance (SDI) on payroll taxes - Documented need of care for parent, parent in law, spouse, registered domestic partner, grandparent, child, or sibling
✓ = (Yes) The policy covers this; X = (No) The policy doesn't cover this					

California’s Paid Family Leave Program is considered a model program

While CFRA and FMLA provide only job protected leave and continued benefits, California’s Paid Family Leave (PFL) offers partial wage replacement for eligible workers while they take leave. For up to 6 weeks per year, PFL compensates working caregivers either 60% or 70% of their normal wages for up to maximum of \$1,216 weekly (as of 2018). Eligible workers pay into California’s State Disability Insurance (SDI) through their payroll tax regularly, and are collectively banking these contributions for possible future use.¹²

PFL is available to workers regardless of how many people are employed at their place of work. Additionally, PFL covers more types of relationships.

Californians can take leave from work to care for a:

- Parents
- Child
- Spouse
- Registered domestic partner
- Parent-in-law
- Grandparent
- Sibling

For these and other reasons, California's PFL has been a model program for states throughout the country.¹³

Californians can participate in these policies simultaneously, as long as they meet the eligibility requirements. However, the eligibility requirements, as well as some of the program features create obstacles for many working family caregivers that result in many not being able to benefit from them.

Family leave policies are not equitable

Although these policies are helpful for supporting working family caregivers, policymakers did not create them in ways that actually serve each and every caregiver, especially caregivers who have more to lose financially.

FMLA doesn't cover 40% of the United States workforce ¹⁴

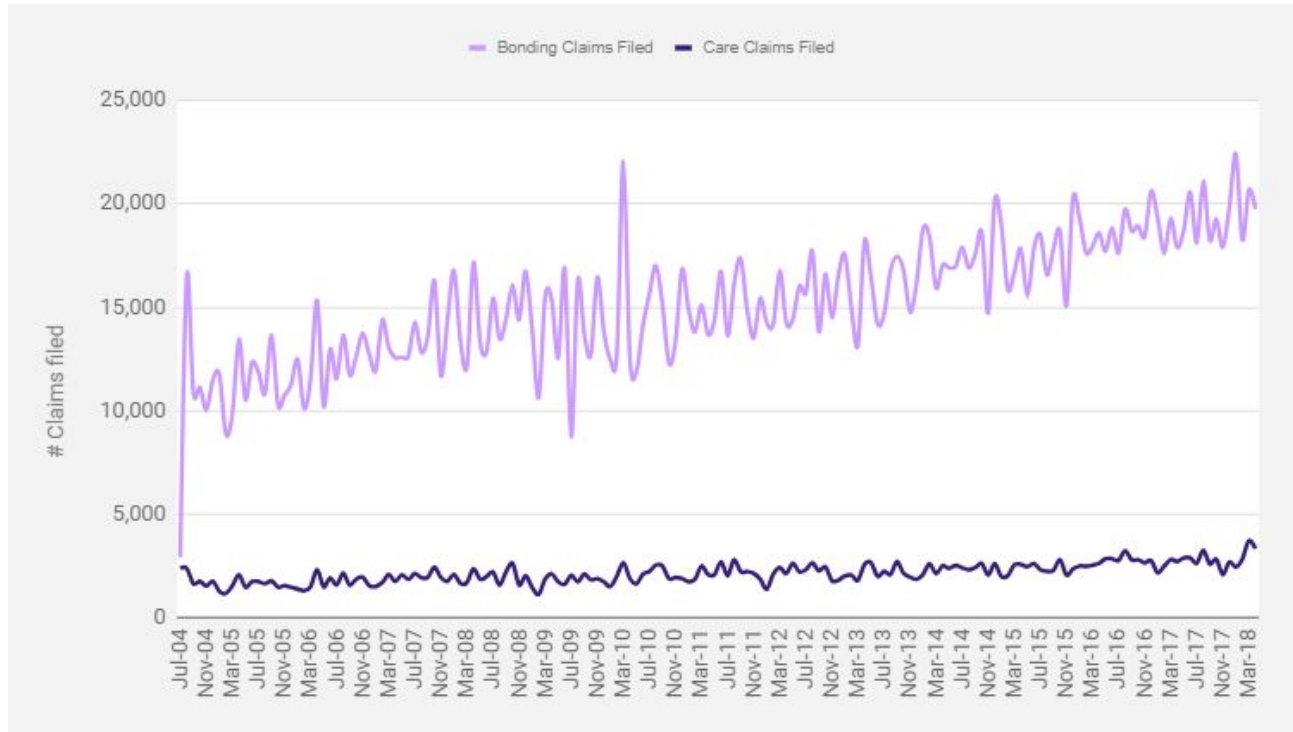
Working family caregivers who are not covered by FMLA or CFRA tend to be employed at small establishments, work part-time, or who have not worked at their job for long enough (which can be the result of high turnover rates at some workplaces, and insufficient working hours provided by some employers).¹⁵⁻¹⁷ Sectors with these characteristics often include retail and service industry jobs, which are typically high-stress and neglect to provide livable wages, paid sick leave, health benefits, and other benefits.¹⁸⁻²¹ Because of the lack of employer-provided benefits in these types of jobs, and because workers are ineligible for state or federal job protected-leave, many low wage workers have nowhere to turn and risk losing their job when they take leave from work to care for their loved ones.

PFL doesn't cover everyone — and those who are eligible are not actually using it

Despite the wider availability of PFL for California's workers compared to FMLA, it's not fully inclusive and provides no job protection. Workers who don't pay into California SDI tax are not eligible because PFL is self-funded through employee contributions. These ineligible workers include contractors, the self-employed, and many public sector employees — unless they opt in.²²

Paid Family Leave is vastly underused by working family caregivers even though many of them pay into the program. As many as 2.5 million caregivers could be eligible for PFL, however less than 1% are actually using it.²³ In its first 10 years of implementation, the Employment Development Department (EDD) processed nine times more PFL claims for bonding, i.e., adoption of a child or the birth of a newborn, than for caregiving, even though caregiving is a prevalent and universal experience. In recent times, bonding claims continue to rise whereas care claims are relatively stagnant.

Figure 1. Trends in PFL claims filed for bonding versus caregiving (2004-2018)



Stakeholders expressed that PFL does not work as well for caregiving as it does for bonding. Part of the reason is that the EDD proactively shares information about PFL with expecting mothers who are on pregnancy disability leave which is also managed by the EDD. A legislative official summarizes:

There's a natural path [for soon-to-be mothers] and EDD took advantage of it with [their proactive outreach]. There's no way [for EDD] to know my mother is ill, but they will know if I'm recovering from delivering a child from using State Disability Insurance."

– Jennifer Richard, Legislative Staff

In comparison to bonding with a newborn, caregiving duties can be unplanned, unpredictable, intermittent, and long-term, which make it challenging for caregivers to tap into PFL.

PFL is underutilized because people aren't aware it exists

Most California voters (57%) are not aware of PFL and 60% of eligible caregivers do not know about it. ^{13,23-24} Levels of awareness are disproportionately lower for:

- **Latinx and immigrant workers:** Latinx workers are about half as likely to be aware of the program than other groups
- **Workers from low-wage, low household income, and low education backgrounds:** Those with a less than high school education are almost one third less likely to have awareness as compared to college graduates

A lot of barriers create obstacles for working family caregivers to know about PFL — if workers aren't aware of PFL, it is virtually impossible to take advantage of it. Low-income and immigrant communities experience greater barriers in accessing PFL for reasons including fears of losing wages and employment, discovery of undocumented status, or lack of translation for educational materials.

Raising awareness of PFL on its own won't make it accessible or equitable

Prior research on PFL tells us why usage is low. Below are reasons why eligible and aware working family caregivers have not used PFL: ^{13,23}

- **Low wage replacement:** caregivers can't afford losing 30% to 40% of their paycheck
- **Fear of job instability:** caregivers are worried that because PFL doesn't provide job protection, they can lose their job if they take leave
- **Employer perception:** caregivers worry that their employer won't approve of their taking time off and that their employer will retaliate against them for taking leave by giving them a worse schedule, not giving them a promotion, or firing them
- **Application process:** the application process is complicated and it's hard to get help from the EDD when filling out the application
- **Cultural relevance of material:** caregivers who speak a primary language other than English share that material is not translated in their language and/or doesn't make sense if it is translated
- **Stigma against using government assistance:** people mistakenly consider PFL a government assistance program or a "handout" that they are embarrassed to use — they may not know that they have been paying into the program

These barriers make it challenging to access supports that were designed to make caregiving easier. We all deserve support when it comes to providing care. We all need to be there for our family and friends. These policies are clearly not set up to benefit all of California's working family caregivers.

California's Paid Family Leave Falls Short

From our research, we learned that working family caregivers often don't know PFL exists, and that they often experience confusion about the multiple family leave policies. Many caregivers would rather not apply for PFL because it means losing wages or their job. When they do apply, they experience barriers with using the program.

Over two thirds of working caregivers don't understand PFL

Where you work and how much you make impact whether you know

According to our statewide survey, awareness about PFL remains less than ideal (66%) among eligible caregivers, and only 31% have an understanding of it. Those in service industries, such as retail are less likely to be aware of PFL than workers in professional types of settings such as health (52% vs. 73%).

Additionally, caregivers who work in higher paying jobs are more likely to know about PFL. For example, prevalence of awareness for people who earned hourly wages up to \$19.99, \$29.99, and \$30+ was 54%, 68%, and 72%, respectively. Just half of workers who earn between \$10.51-\$13.99 know about PFL. These trends are similar for workers according to their household income level, for example 72% of those with a household income of \$60,000+ knew about PFL versus 55% of people in the lowest income bracket (\$0-\$44,999).

Finally, caregivers working in places with more employees are generally more likely to be aware of PFL. Almost three-quarters of people in environments with 50+ employees knew about PFL compared to 63% and 53% of caregivers in workplaces with 11-19, 1-10 people respectively. Caregivers working in environments with 50+ employees were also more likely to say it was easy to understand PFL, and they are more likely to understand it well enough to explain it to someone else versus employees from smaller establishments. Environments with more employees could be more resourced and have a robust human resources structure that could support educating employees about legal rights and benefits.

Caregivers are confused by the multiple laws

It is not uncommon for caregivers to be unsure of what they are eligible for, for example 20% of working caregivers — 1 in 5 — who are eligible and aware of PFL did not think they qualified for it.

"I was confused between the federal family leave coverage, which is not paid, and California's Paid Family Leave. I knew there was an ability to get paid family leave. I wasn't even terribly clear that it was state based versus federal so when I initially did the paperwork I did the federal paperwork when I should have done just the state paperwork."

– Amanda, caregiver to father recovering from cancer diagnosis

Advocacy groups spend hours advising caregivers about their rights based on unique working and caregiving situations, and support caregivers with navigating the application process. An advocate sums up the problem of having a patchwork of family leave laws:

“I think one of the most difficult things about our patchwork of laws, is that it's not simple, you actually have to be aware of a number of different programs and laws in order to have the full picture of what your rights are.”

– Sharon Terman, advocate

Employers could use some guidance

The workplace is the most common place that working family caregivers learn about PFL (46%). However, for many, this environment may not be conducive to accessing PFL for several reasons.

Advocates share that employers do not themselves understand PFL and therefore are not equipped to explain it (well) to their workers. Employers are also not held accountable for not sharing information about PFL, which they are required to do by law.

In some work environments, human resources activities are contracted to companies outside of California. These companies may not know about or understand California workplace policies. As a result, working Californians could be misguided.

Additionally, human resources departments may not exist at all in some work environments. A stakeholder shared that low-income people and people of color tend to work in environments where a strong human resources structure does not exist, and as a result, many people who are already vulnerable to economic instability do not learn about their right to PFL.

Barriers to participate in PFL are worse for low-wage workers

Caregivers — especially older workers and immigrants — are fearful of losing their job and their wages if they apply for PFL

Awareness of PFL does not guarantee that working caregivers will apply for the program. Almost 2 in 3 of eligible and aware working caregivers who completed the survey, did not consider applying for PFL. In fact, just 16% of eligible caregivers who know about PFL have ever applied for it.

Job loss and employer retaliation are a concern (and a consequence) for workers and could prevent them from using PFL. Workers could face consequences at work if they take leave, including being let go, missing out on promotions, and having hours cut by employers. Also, job protection is not part of PFL, which puts workers at risk of losing their job.

“Why am I going to take off a few weeks but then in the long-term be unemployed?”

– Sophia Cheng, advocate

Low wage workers have more to lose when it comes to taking PFL. The 60% or 70% wage replacement is not enough for many families when every dollar counts toward sustaining their families and children — “70% of minimum wage is still really really low” (Sophia Cheng, advocate). An added layer is that wage replacement from PFL is taxed, and this sort of income will not go far to accommodate California’s expensive standard of living.

Low-income workers, women, older workers, and immigrants, experience added burdens for taking leave from work. Often the intersections of these identities can mean cumulative stress. Women are more likely to take on caregiving roles and also earn less than male counterparts, and therefore, they are more likely to experience economic instability due to caregiving duties. When women who provide care are low-income, they are especially prone to experience poverty. Older workers are also in a vulnerable situation due to age discrimination.

“If you’re a low income older worker, you might be easier to replace”

- Donna Benton, advocate

Undocumented, immigrant workers, and people who may not speak English feel especially vulnerable to retaliation in the workplace. “Undocumented workers have a lot of questions about whether or not they qualify to take PFL....the combination of not being sure of whether or not they qualify, and and also the general immigration climate, a lot of immigrants are fearful of having any type of interaction with government agencies” – (Sophia Cheng, advocate).

Applying for PFL can be a source of frustration

Advocates and caregivers reveal that administrative barriers with the implementation of PFL are just “not worth the effort” for already overwhelmed caregivers. Some common concerns with accessing PFL include calling the Employment Development Department (EDD), accessing intermittent leave, the application process, and language access.

“The times I cried since then have been directed at PFL. After the initial diagnosis of course and the shock of all of that, you know my dad having cancer and having emergency surgery... but the times I have cried since then has been over this stuff. It is maddening.”

- Amanda, caregiver to father diagnosed with cancer

Caregivers who call the EDD express a lot of frustration with not being able to speak with someone over the phone, staying on hold for long periods of time, and even experiencing poor or rude customer service.

“If you actually call the EDD hotline, the phone number, you literally usually cannot talk to anyone.... I’ve called upwards of ten times. And number one no one answers the phone. Number two, there’s no way to leave a voicemail. And a lot of times you’ll

go to ringing for a while; it'll go to an automatic voicemail saying, 'You've reached the maximum number of people who can wait on the line. Goodbye.'"

– Sophia Cheng, advocate

Common frustrations with the application process include not receiving confirmation, long waiting periods, technical issues with the online application, and coordinating documentation needs with physicians.

"My husband has leukemia, and his primary care physician said to talk to his oncologist; the oncologist said to speak with the primary care provider. I feel the physicians are afraid they will get in trouble for supporting employees that need this benefit."

– Maya, caregiver to husband undergoing cancer treatment

Advocates and caregivers also point to how PFL is complicated to use for intermittent leave, which consists of taking hours, days, or weeks of leave over a longer period of time, as opposed to a continuous block of 6 weeks off.

Advocates further reveal that material for non-English speakers is not in enough different languages and is not translated well (if it is translated). As a result, communities can face difficulty making sense of valuable information, even if it is in their own language.

"The challenges for those groups are just magnified because often materials coming out of the agencies are not in own language or are not easily accessible, and often those are workers who feel already quite vulnerable in their jobs."

– Jenna, advocate

The EDD is attempting to reduce barriers for caregivers to use PFL by offering application documents in more languages and improving the intermittent leave application process. High call volumes are among the top issues they're working through internal system and resource constraints to resolve.

"[Over] 17 million Californians pay into this program. We probably get 4 million plus calls every year, and probably answer 1 million plus. [If we] better utilize technology we can provide a better customer experience. A very high percentage responded [to our annual survey] that they were pleased with their customer experience, so we know we are making some improvements."

– EDD staff member

Recommendations to ensure that PFL works for everyone

Almost a quarter of caregivers who are eligible and aware of PFL would like better education about it (24%), followed by guaranteed job protection (19%), and better wage compensation (17%). Policymakers and the EDD could improve PFL by focusing on these priorities, and improving the application process so that PFL is advantageous and accessible to caregivers.

1. Policymakers: make PFL comprehensive

Use of PFL is severely limited by two barriers: it doesn't provide job protection, so caregivers are reliant on FMLA or CFRA, which don't cover workers at smaller places of work, among others; and it doesn't provide complete wage compensation. Both of these aspects affect low-wage workers more severely than higher wage workers. California policymakers should make job-protection available to all PFL eligible employees and increase the wage replacement rate, especially for low-income workers.

"When I returned to work at the end of the leave, they "let me go" for "non-performance of my job" with one month's pay as severance. We need job protection as part of the family medical leave. My employer "let me go" because of "non-performance" of job because I took time off under the Paid Family Leave"

– Raj, caregiver to wife with severe brain injury

Lawmakers should also increase the length of time during which workers can receive PFL. Working caregivers spend an average of 5.2 years caring for their loved ones and an average of 36 hours/week on care duties — another job! Six weeks of partial pay per year is inadequate: there is “not enough time in the program to really matter” as one caregiver puts it. And even workers who qualify for FMLA or CFRA leave are only entitled to 12 weeks of job protection. If they need more than 12 weeks off to care for a loved one, they can be fired. Other states, such as Washington and New York, have passed legislation to allow pay for as long as 12-18 weeks. Some states, such as Rhode Island, also include job protection as part of their paid family leave policies.²⁵⁻²⁶

Additionally, almost 1 in 10 working caregivers care for someone who is not listed as an eligible family member. These relationships include friends, fiances, aunts, uncles, nephews, nieces, cousins, and brothers-, sisters-, sons-, and daughters-in-law. The family relationships for which caregivers can receive job-protection is even more limited. For communities of color who traditionally live with multi-generational and extended family, nurturing these types of relations is important.

Furthermore, LGBTQ caregivers may care for chosen family rather than biological family. Lawmakers must make PFL more useful, as well as culturally sensitive, by expanding who workers can care for while receiving PFL and making job-protection available for a larger variety of relationships.

2. EDD: ensure that information about PFL is widely available through diverse places and channels

Advocates express that the EDD has not carried out enough education about PFL to saturate public awareness. The EDD recently initiated efforts to increase awareness through a multimedia campaign and has plans to evaluate its success. The EDD can increase public awareness by more actively engaging community/advocacy groups, employers, and settings that caregivers engage with regularly, such as the medical setting.

Community organizations are well equipped to understand caregiver communities. Caregivers have shared that they would rather learn about PFL locally, from people they trust and know, rather than politicians or government agencies. Additionally, advocacy groups are expert at knowing how to best reach communities they serve, especially those who are typically hidden, like immigrant groups. The EDD should collaborate with and invest in community partnerships so that these “trusted messengers” can effectively and efficiently connect with communities who can benefit from PFL.

“[Employers] are impressed and excited about PFL. It is a payroll deduction, an employee-only contribution. The biggest benefit is that... it is administered through the state, so they don't have to take on that additional cost or complexity. At the same time, they're able to ensure their employees are able to take the time to spend with a child or take care of an elderly adult or other family member that needs help.”

– Mark Herbert, California Director for Small Business Majority

Small Business Majority is an advocacy group that delivers workshops and education to small businesses on various workplace policies, including PFL.⁽²⁸⁾

According to our survey, the workplace was the leading source of awareness about PFL, and was associated with stronger understanding of it compared to other sources. The EDD, as well as organizations that educate small workplaces, like the Small Business Majority, should see that employers and human resources professionals know about PFL and other family leave laws comprehensively, for example through training or certification. Educational efforts should also include information on employee rights and employer consequences for retaliation against employees. Unions are an effective source of information in the work environment as well — and can play a leading role in dispersing information about PFL.²⁷

“Even if you as an employer don't like policy, you need to understand how you're legally obligated and liable if don't follow it...I don't want just to know what I have a right to. I want to know how is this actually going to work when I run into problems”

– Sophia Cheng, advocate

The medical setting was frequently mentioned as an ideal source of information about PFL. It is understandable that caregivers will interact with medical professionals to coordinate the care of their loved ones. Both advocates and caregivers suggested the medical setting be a place to learn about PFL and to receive support in completing the application, particularly because documentation from physicians is required for the application.

Finally, stakeholders share that the EDD could improve the information it makes available through the web. Their website could do a better job at educating caregivers about related policies, including FMLA and CFRA. It could also reorganize its website structure for clarity — learning about PFL through the EDD’s website is counterintuitive because information about PFL is located alongside unemployment resources, whereas eligible and potential PFL applicants must have worked and paid into SDI via payroll taxes to apply.

“The name of the website, the EDD, I just think about it, I would have never known. How is that even related to paid leave? I would think it has to do with helping people get jobs. To me I wouldn’t have gone to this website, right? Because I was employed. It seems strange to me.”

– Omar, caregiver to brother with a mental health condition

3. EDD: continue to improve the PFL user experience

Even if caregivers learn about PFL and have every intention to access it, they could experience challenges in using it. Caregiving is stressful enough, which is why the application process should be as accommodating as possible.

“I didn’t have the time or energy to figure out the process. It seemed too complicated and all my energy was used as the only caregiver to my family member”

– Ellen, caregiver to mother with dementia

Some additional recommendations, in light of the barriers include:

- **Improve customer service:** Caregivers would like to be able to speak to someone over the phone, engage with friendly and understanding staff, avoid lengthy wait times, and have an easier time accessing their assigned case manager.
- **Streamline the application process:** Caregivers would like updates on their application status, and would like to be able to submit their paperwork online in a straightforward way, including medical documentation.
- **Enhance intermittent leave:** Caregivers would like to see an efficient process for intermittent leave as it currently requires coordination and processing of multiple timesheets.

The EDD is addressing many of these barriers and it may take time to see the effects of their changes. In partnership with advocacy groups, the EDD should share, and evaluate changes with input from economically and racially diverse caregivers.

The EDD should also acknowledge unintended consequences of their policies and practices. A helpful resource for the EDD is the Government Alliance on Race & Equity, a network of government workers working towards advancing equity.²⁹



A caregiver shares a laugh, and a selfie with her grandmother

Workplace Supports Help Some Out

If most working caregivers are not using PFL, how are they making time to provide care? Advocates and caregivers share that they [caregivers] are “finding ways to make it work.” This includes using employer-provided paid time off from work, and shifting their work schedules. However, we learned that these workplace supports are not available to all caregivers.

Caregivers are using other workplace supports instead

California PFL is just one type of workplace support. Other workplace supports include:

- Schedule predictability, consistency, and flexibility
- Paid time off including vacation time, sick time or sick leave from employers
- Employer-provided (paid) leave

Workplace supports related to health and long-term financial stability of workers include health insurance and retirement plans. Some supports, such as paid sick leave, are mandated by local and state law, most however, are at the discretion of employers.

Paid sick leave is required by law in California

Some cities, like San Francisco, have more progressive policies

State of California Healthy Workplaces, Healthy Families Act (2014):

Employees who work with the same employer for 30+ days are entitled to paid sick leave ³⁰

- Employees earn at least 1 hour of paid sick leave for every 30 hours they work
- Employees can take paid sick leave for their own health or a family member’s health
- Employers can limit employees’ use of paid sick leave to 24 hours or 3 days per year
- Employees can also impose a 48 hour, or 6 day cap on accrued paid leave

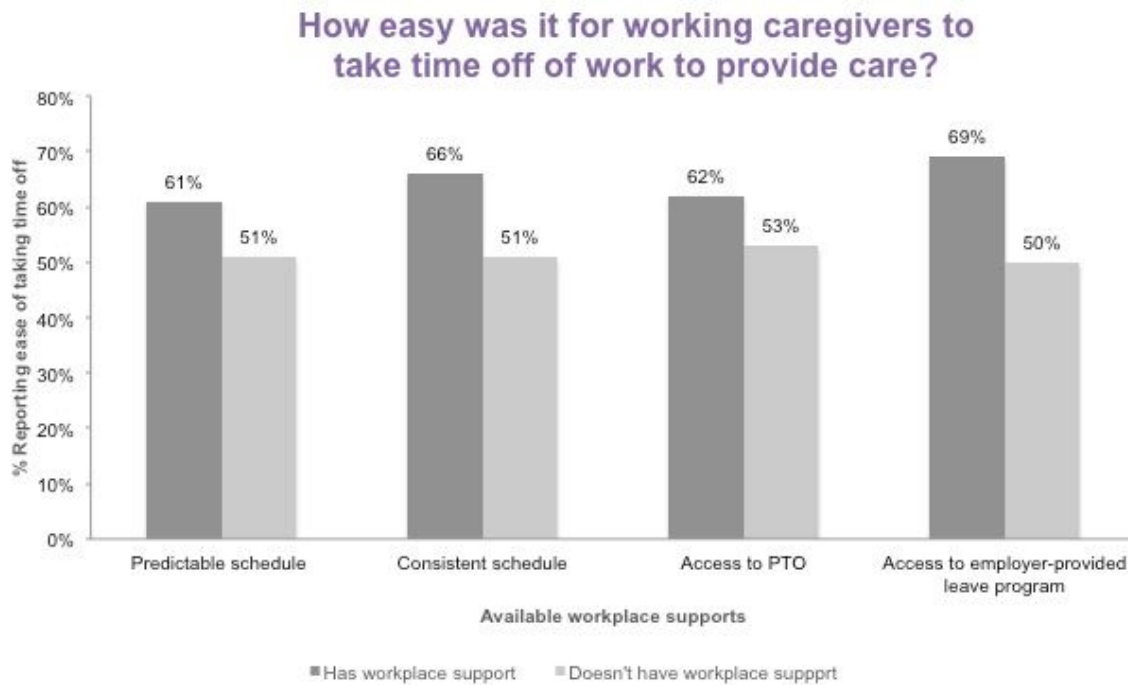
San Francisco’s Paid Sick Leave Ordinance (2007; amended 2017):

Employees are entitled to paid sick leave starting their first day of employment ³¹

- Employees can earn at least 1 hour of paid sick leave for every 30 hours they work
- Employees can take paid sick leave for themselves, a family member, or designated person
- Employers with 10+ employees must allow employees up to 72 hours or 9 days of paid sick leave
- Employers of smaller businesses can limit paid sick leave to 40 hours or 5 days

The survey revealed that more than 40% of caregivers who are eligible and aware of PFL resorted to other workplace supports. About 32% of working family caregivers used PTO and/or took advantage of employer-provided flexible workplace options, including shifting hours, working from home or working part-time. In general, much of the broader community of working caregivers (84%) ends up taking time off of work to care by using paid time off such as vacation time or sick time, or changing their schedule.

Having these supports means that working caregivers have a much easier time taking time off of work to care.



Supportive workplace accommodations, such as flexibility makes it possible for working family caregivers to provide care:

"I am extremely lucky in that I was able to find a job that has allowed me the flexibility to care for my aging parents through their health crises, as well as support my kids as they grow up. I took several years off work because I could not find a job that would provide the flexibility and hours I need. I only started working again when I found an employer that would be able to support my needs."

– Leslie, caregiver to aging parents

Having rigid work environments makes it extremely challenging, and essentially impossible to make time to provide care:

“If I was a typical working parent, that had to be at my job working 9-5 every single day, it would be nearly impossible. I just couldn’t imagine being at a job where you really had to be there and clock in and provide services on the spot and clock out. It just, it would be entirely too stressful. Everyday’s not the same. I need to be given that flexibility because of the unknowns of each day”

– Amanda, caregiver to son with chronic condition

Additionally, having an empathetic and understandable supervisor makes a world of difference. Working caregivers shared stories of the support from their employers and coworkers who were also in similar positions, and/or participated as an advocate of their caregiving colleague:

“She herself [employer] has an aging parent and was very good about recognizing that I would feel better as a person if I went there [to be with my mother] when I was debating if it was a good time to go. She prioritized that.”

– Flora, caregiver to mother with terminal illness

But not everyone has workplace supports

Not everyone has access to these supports. Surveyed caregivers with higher wages have more schedule consistency (57% vs. 48%), predictability (87% vs. 77%), flexibility (72% vs. 65%), PTO (83% vs. 56%), and were more likely to have health benefits (84% vs. 51%), a retirement plan (81% vs. 42%), and employer-provided paid leave (56% vs. 21%) versus low wage workers.

More than half (51%) of working caregivers who earned low wages had to take *unpaid time off of work* as compared to 30% of higher wage caregivers. These low-wage workers have fewer resources to start with and can least afford to take unpaid time off. For low-wage workers — who often have to pay for healthcare out of their own pocket — the effects of unpaid time off are more pronounced on their health and long-term prosperity. The income lost could be going towards funds for healthcare and retirement, which employers don't often provide.

Workplace supports were more prevalent in places with 50+ employees compared to smaller companies or organizations. Additionally, specific categories of workers were overall less likely to have PTO, health benefits and retirement benefits, including workers in the hotel industry, arts/recreation, and those in construction:

- 31% of construction workers have access to PTO vs. 77% of workers in other industries
- 42% of arts/recreation workers had a retirement plan through work vs. 71% of workers in other industries
- 44% of arts/recreation workers had health benefits through work vs. 77% of workers in other industries

Some employers retaliate against employees through severe consequences for trying to take time off of work. In worse cases, workers can quit their jobs and/or retire prematurely, or be fired.

“This is very stressful I worry constantly about my mother and job. Getting time off from my employer is very difficult and they have very retaliatory behavior towards employees when they take time off. When you come back to work they schedule you to work 10 days in a row for work to punish you for taking time off.”

- Jackie, caregiver to stepmother with chronic illness

Contract workers make up the fastest growing segment of the workforce.

“For those in the gig economy this is a serious issue. I had to rely on financial support from other family members when my young adult son was psychotic and suicidal and couldn't be left alone.”

- Justin, caregiver to son with mental health condition

In light of a rising “gig economy,” (defined as a labor market with short-term contracts or freelance work rather than long-term, permanent jobs), we need to understand the unique work situations of contract workers, who:

- Don't qualify for California PFL
- Don't have access to a lot of workplace supports that employed caregivers do:
 - ◆ **69%** of contract workers who provide care have *predictable schedules* vs. **85%** of employed caregivers
 - ◆ **24%** of contract workers who provide care have *paid time off (PTO)* vs. **78%** of employed caregivers
 - ◆ **39%** of contract workers who provide care have *health benefits* from work vs. **77%** of employed caregivers
 - ◆ **35%** of contract workers who provide care have a *retirement plan* from work vs. **72%** of employed caregivers

This could change however. A recent California Supreme Court decision ruled that many workers currently classified as “contractors” by their employers may actually be employees, and thus eligible to receive workplace benefits.⁽³²⁾

Recommendations to improve access to workplace supports

For caregivers who don't know about PFL or experience challenges in accessing it, support from their employer could be the only option for taking time off from work to focus on caregiving. However, not all working caregivers have employers that provide paid time off or scheduling flexibility. Low-wage workers have the fewest of these resources. Additionally, these workers are also more likely to lack access to key benefits such as health insurance and retirement plans which are important for their wellness and long-term economic stability.

1. Employers and policymakers: provide accommodations beyond leave

Employers should work directly with their caregiver employees to create schedules that make sense for them. Every family caregiving situation is different, which is why workers need tailored accommodations. Accommodations for individuals with disabilities and pregnant women — including flexible schedules, working remotely, or time off from work — can serve as a good model to draw upon for providing flexibility to caregivers. Lawmakers should make accommodations available to caregivers.

Employers should also be creative, resourceful, and open-minded about exploring additional solutions for their staff who care for a loved one. Employers can institute their own family leave policies such as providing pay during leave, and providing additional leave beyond state and federal policies.

Research shows that greater supports like flexibility can lead to greater productivity, greater job satisfaction, and lower work-related stress.³³⁻³⁵ Empowering employees, through having a choice in their work hours, can be an important mechanism for these outcomes.³⁶

2. Employers and policymakers: ensure livable wages, health benefits, and retirement benefits

Caregivers spend a lot of personal financial resources on caregiving needs, and much of this investment in their loved one could mean disinvestment in their own short-term and long-term health and financial stability. Employers and lawmakers across the state should strive to continue increasing the minimum wage in relation to increasing costs of living. In 2023, the California state minimum wage will climb to \$15/hr from approximately \$11/hr in 2018. Policy experts have found that a \$15 minimum wage for example, will lead to improved economic well-being for workers and their families, as well as positive outcomes for employers.³⁷ For caregivers, whose expenses are often higher, employers and lawmakers should see that wages truly are livable.

"I am fortunate to have a well paying job. I can't imagine how others do this"

– Christina, caregiver to mother and sibling

Investment in workers is good for employers as well — research shows that increases to minimum wage increase worker productivity and decrease turnover.³⁷ Benefits like health plans can also make jobs attractive and limit turnover.³⁸

Beyond Policies and Workplace Supports

Eliminating hurdles in accessing time off from work through PFL and/or through workplace supports can mean that working caregivers are less likely to lose their source of income. This is an ideal situation and such progress will make an incredibly positive impact for working family caregivers. However working caregivers will continue to need additional supports.

Caregiving for a loved one is a challenging undertaking

Becoming a caregiver requires learning new skills

Entering the role of caregiving is new territory for many caregivers, and this means learning how to provide care and also remember to care for one's self.

"There were so many things I needed to learn, both about being a caregiver- I don't have a medical background at all - but then there were things about the healthcare system ... that took time and energy."

- Oscar, caregiver to sister with disability

Some of the common challenges that caregivers face are understanding the technical aspects of providing care. For caregivers who are not trained as nurses or doctors, learning how to administer medication, treat wounds, and so on can be new and intimidating. Caregivers even equate caring for elderly family to caring for a newborns: "I felt like for the first time I had experienced what it was like to have a newborn," a caregiver shares.

Another issue that is extremely stressful is navigating the complex health system. Caregivers experience frustration with all aspects of accessing healthcare for their loved one, including dealing with insurance paperwork, coordinating care with providers, and scheduling appointments.

"It's a ridiculous way that the health care system is setup, that is very stressful. After the initial diagnosis, and the shock of that, dealing with payments, setting up appointments and care coordination has been the worst."

- Margie, caregiver to cousin diagnosed with serious health condition

Being a caregiver requires self-care — a challenge with limited time

With all the time that caregivers spend caregiving on top of working, it's not surprising that they have very little time left for themselves. Caregivers feel exhausted and even feel guilty spending time on their own needs. Learning to negotiate their needs can be a difficult:

"I thought I could handle it, but I got burnt out. It is very emotionally draining. I had to get therapy for almost 6-8 months. I mean, I went into depression too, to be

honest ... You know, just as any other caregiver, sometimes, we often feel we haven't done enough for caring for the loved ones. And that's the kind of guilt that gets into you. As the time got by, I learned how to manage it better – I don't let the guilt get into my mind, because if I do that, I would not be able to be a better caregiver for my mom. I just have the thinking that I tried my best. Before you take care of her, you have to take better care of yourself. And it's a challenge. It's as easy to say, but it's a challenge to put into practice."

– Tony, caregiver to mother recovering from a stroke

Caregivers also shared that other stressors include family dynamics and relationship quality: "stress on marriages for caregivers and their partners is incredible."

The mental and physical health and well-being of the caregivers themselves are important to take into account when thinking about improvements to caregiving.

Many who work and care for loved ones feel stuck between two worlds. They feel like they can't do a good enough job in either role, and end up feeling defeated. At the same time, working caregivers are grateful for work — they call it an escape and a way to hold on to their identity.

"It was good for me to be able to work, but it was hard to feel like I was doing great job at my job and a great job as a caregiver."

– Ellen, caregiver to best friend recovering from a fall

"[If] I was with my mom, I [felt like I] was letting down my employer and [not] keeping up my end of responsibility. I always felt like I should be with my mom. I was always thinking I was in the wrong place wherever I was. That was challenging. I was exhausted."

– Pamela, caregiver to mother with terminal illness

Caregiving for a loved one is a social benefit

Working family caregivers are greatly undervalued

Caregivers in California provide almost \$58 billion in unpaid services to loved ones every year — services that would otherwise be financed by the Medicare system and taxpayers.¹ Simultaneously, caregivers put their own financial stability at risk. A greater valuation of caregiving responsibilities can help advance policies to support working caregivers — policies that serve each and every one of them.

Legislation for bonding has gained traction recently. For example, last year, SB 63 enhanced PFL to include job protection for up to 12 weeks for new parents.³⁹ A caregiver highlights how the differences in workplace values for bonding versus caregiving:

“Most companies tout flexibility for child care issues but fall flat when dealing with elder care issues. They don't walk their talk and this is a big problem for baby boomers.”

- Jin, caregiver to elderly mother and father

We need a similar focus on improving policies for working caregivers. In general, societal emphasis on supporting caregivers falls short. Ai-Jen Poo, the Director of the National Domestic Workers Alliance shares what needs to happen to put family caregivers — often unseen — in the forefront.⁴⁰

“We believe we need a whole new approach to caregiving in America, one in which we invest in care as infrastructure – as the work that makes all other work possible. When we invest in the ability of families to pay for the care they need, and the workforce whose job it is to support families can earn a family - sustaining wage, then we have a system that is sustainable. We can create good care jobs and support the productivity of tens of millions of working family caregivers at the same time.”

- Ai-Jen Poo, Activist and Labor Organizer

Recommendations to protect the well-being of caregivers

It is possible for working caregivers to be good employees and good caregivers. Ensuring that workplace policies are effective in serving all caregivers is an important first step. However, legislators must also see that California’s caregivers are more than “present” or “available” for their caregiving duties. In fact, they should be thriving, as individuals, and in all of their roles. Caregiver training, healthcare plans, supplemental income, and a network of support will do that. As one caregiver puts it, “caregivers need much more support for everything!”

1. Policymakers: ensure that working caregivers have access to health insurance

Because of the significant time and labor intensive energy that goes into working and taking care of loved ones, caregivers should have the opportunity to look after their own well-being. Employment is not a guarantee that working caregivers will have access to health insurance and not everyone — especially low-wage workers — have access to affordable healthcare. A state-provided health insurance program or subsidy for paying for existing health care premiums specific to working caregivers (and one that includes much needed mental health and stress management services) can allow caregivers to tend to their own minds and bodies.

Next, existing health services for caregivers should meet caregivers where they are. Some caregivers express frustration that they could not attend support groups as much as they

wanted to because they were too busy providing 24/7 care to their family member. Providers should offer services at times that caregivers are available, or, better yet, programs could be virtual or mobile to see that caregivers can actually access programs created to benefit them.

2. Policymakers: guarantee economic security of caregivers

Accessing PFL can provide some financial support, but insufficient wage replacement continues to be a barrier in utilizing PFL. Other workplace supports like paid sick time or vacation time can help, but may be insufficient or nonexistent for workers, such as those who are low wage or working in the service sector.

We need a tailored approach to see that financially-strained working caregivers don't fall into poverty and don't unwillingly retire prematurely. Many caregivers need supplemental income to accommodate even basic needs, like paying utility bills and purchasing groceries. Caregivers could benefit from a tax credit given the thousands of dollars in out-of-pocket expenses they spend annually on care. An existing current federal tax credit for caregivers has stringent eligibility requirements and doesn't cover most caregivers. At the state-level, advocates and legislators are in talks about a more encompassing tax credit program.⁹

Another method is guaranteeing social security. The Center for Community Change is working on a "caregiver's credit" which would provide social security for up to 5 years when caregivers are not in the labor market or are working reduced hours due to caregiving duties.⁴²

For caregivers who can't afford to exit the workforce, hiring an In-Home Supportive Services (IHSS) provider to care for their loved one can be a solution.

IHSS provides support services such as personal care, grocery shopping, and accompaniment to medical appointments. If you receive Supplemental Security Income (SSI) or meet all Medi-Cal income eligibility requirements, you may be able to receive IHSS services. (41)

Alternatively, caregivers could inquire about becoming an IHSS worker and be paid for tasks they already perform, thus maintaining financial stability.

Financial support and credits must serve a broader group of working caregivers. Many middle-income caregivers express that they don't qualify for programs serving low-income earners, and don't earn enough income to hire extra help, or end up living paycheck to paycheck if they hire help.

"Financially we fall right in between. We don't earn enough to be able to afford home care or assisted living. I've relied on family and friends to fill in because I can only afford someone in the home a few days a week. And we earn too much to qualify for any type of assistance."

-Ami, caregiver to mother-in-law with Alzheimer's disease

In California's economic climate, both low- and middle-income earners could be at risk of falling into poverty and policy efforts must account for both to advance economic stability.⁴³

3. Funders: provide funding to organizations serving caregivers to increase opportunities for training and resources

Caregivers report having to learn about all aspects of caregiving and the health system. Caregivers need resources that help them carry out their tasks more confidently and effectively. Accessible and formal training on how to be a caregiver would benefit caregivers immensely:

"I think it would be a good idea to get the certification, or maybe a workshop to reinforce what we're already doing but to get the certification to work to care for other people"

- Alex, caregiver to elderly neighbor

Caregivers also expressed a desire to learn about managing finances, which is not a surprise given the financial toll that caregiving takes. Learning the financial part of caregiving would also be useful information.

Caregiver Resource Centers throughout California, as well as additional community-based organizations and public agencies should receive funding to implement and standardize such training programs and educational workshops on topics that caregivers request. These centers experienced cuts in funding years ago and require attention to assure that resources are available and accessible for family caregivers moving forward.

4. Advocacy groups: keep prioritizing and investing in networks of support and be funded to do this important work

Caregivers can't do it all alone. The African proverb "It takes a village to raise a child" is accurate for not only the day-to-day raising of children, but for caring for the ill, especially the terminally ill, who are at the end of their lives and need support with everything.

"It's really tough to find out about all resources that might help with caregiving -- caregivers end up feeling like failures because they can't do it all"

- Laura, caregiver to partner with chronic illness

Caregivers who are successful in balancing work and caregiving roles depend on a network of people to be reliable and supportive in their varying capacities. This includes doctors, nurses, their employers and coworkers, partners or spouses, and other family members. This help comes in the form of emotional support, bringing over dinner or groceries, or to just giving them a break for an hour or two. Not all caregivers have the benefit of a strong social and collaborative network or team, which is why strengthening community organizations and their outreach efforts to connect caregivers to resources and programs could make an important impact. Even agreements within the family could create a shared understanding of expectations of care and spread the responsibility. This is something that community organizations can assist with.

Conclusions and Recommendations

California's working family caregivers are dedicated individuals — they labor during the day (and/or night), and in the few hours in-between, and on days off, they care for a parent, a child, a partner, or another loved one. They do this with passion and pride, to ensure that the person who matters so much to them is comfortable and well. Most caregivers work, and they must continue to do so to keep up with cost of living, the out-of-pocket costs of caregiving, and to sustain their own identity.

Chances are that we will all be caregivers at some point in our lives. Family caregivers provide a great service to the state and country and we must see that their health and wealth is not compromised for the sacrifices they are making.

Workplace policies and supports for family leave at the federal, state, and places of employment exist but don't adequately serve all working caregivers. Different groups of caregivers experience different barriers. For example, caregivers who work low-wage jobs or come from immigrant communities or communities of color are less likely to know about supports, less likely to have access to them, and experience greater burdens in using them. Women are more likely to enter caregiving roles than men and are more likely to be financially unstable as a result of doing so. Older workers may struggle with finding and keeping work.

A call to improve conditions for California's working caregivers

Intentional improvements to family leave policies and employer-provided supports can ensure equitable access across all fronts. We provide recommendations for improving PFL, workplace supports, and other supports to benefit all of California's vital working caregivers.

Recommendations for policymakers

- Make PFL comprehensive to include job protection and better wage replacement, and expand PFL to cover a greater length of leave and more types of relationships
- See that working caregivers have health care so that caregivers who are at risk of poor health outcomes, do not compromise their own well-being
- Guarantee financial stability to account for the cost of living, especially for caregivers; income can consist of funds for basic needs, tax credits, or social security credits
- Protect caregivers by advocating for workplace accommodations, so that caregivers do not risk their job when they need a flexible or predictable schedule or time off from work

Recommendations for the Employment Development Department

- See that education about PFL reaches everyone, including employers who should explain the policy to employees, medical professionals who play a role in the PFL application process, and community organizations who are most trusted to deliver this information

- (Continue to) improve the PFL user experience — including improving the caller experience, the application process, intermittent leave, and testing improvements with caregivers

Recommendations for employers

- Provide scheduling flexibility to employees, and this includes schedule predictability and options to adjust hours, and even work remotely if possible
- Provide liveable wages, health benefits, and retirement plans to support the short- and long-term economic stability and livelihood of working family caregivers
- Provide additional leave and pay during leave beyond what is required by law. Caregiving responsibilities can last for long periods of time and many employers have the resources to provide more than the state-mandated minimums.

Recommendations for advocacy groups

- Offer opportunities for technical training and resources so caregivers feel confident and comfortable with caregiver duties and navigating the health system
- (Continue to) prioritize and invest in networks of support because caregivers can't do it all alone. They need social, emotional, physical support, and a team of advocates
- Community and advocacy groups need funding to do this crucial work — public and private funding agencies should invest in supporting the efforts of these organizations

As working individuals and families come together and deliberate what needs to be done to see that their loved one is comfortable and thriving, our policies, which reflect and dictate much of our values as a society, must begin to consider what California's working family caregivers endure daily. And, these governmental and institutional policies must be modified to truly serve and benefit those who care rather than create challenges and obstacles along the way, "It gets real hard sometimes to do both, work and take care of your loved ones. Hopefully something can help."



A group of working family caregivers in Los Angeles, California

References

1. Reinhard SC, Feinger LF, Choula R, Houser A. Valuing the invaluable: 2015 update. July 2015.
<https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>
2. Family Caregiver Alliance, National Center on Caregiving. Impact of Caregiving on Caregiver's Physical Health. Updated 2016.
<https://www.caregiver.org/caregiver-statistics-health-technology-and-caregiving-resources>
3. Pinquart M, Sorensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*. 2003; 18(2):250-267.doi: [10.1037/0882-7974.18.2.250](https://doi.org/10.1037/0882-7974.18.2.250)
4. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver Burden. *JAMA*. 2014;311(10):1052. doi:10.1001/jama.2014.304
5. AARP Public Policy Institute. 2015 Report Caregiving in the U.S. June 2015.
<https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
6. Family Caregiver Alliance, National Center on Caregiving. Caregiver statistics: Work and caregiving. Updated 2016.
<https://www.caregiver.org/caregiver-statistics-work-and-caregiving>
7. Span P. Work, Women, and Caregiving. November 2013.
<https://newoldage.blogs.nytimes.com/2013/11/21/work-women-and-caregiving/>
8. Rainville C, Skufca L, Mehegan, L. Family caregiving and out-of-pocket costs: 2016 report. November 2016.
https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2016/family-caregiving-costs.doi.10.26419%252Fres.00138.001.pdf
9. California Task Force on Family Caregiving. Picking up the pace of change in California: A report from the California Task Force on Family Caregiving. July 2018.
<http://tffc.usc.edu/2018/07/02/final-report-from-the-california-task-force-on-family-caregiving-2/>
10. United States Department of Labor. FMLA (Family & Medical Leave).
<https://www.dol.gov/general/topic/benefits-leave/fmla>
11. State of California, Department of Fair Employment and Housing. PDL, CFRA, and FMLA Requirements and Obligations.
<https://www.dfeh.ca.gov/resources/frequently-asked-questions/employment-faqs/pregnancy-disability-leave-faqs/pdl-cfra-fmla-guide/>.
12. State of California, Employment Development Department. About Paid Family Leave.
http://www.edd.ca.gov/Disability/About_PFL.htm
13. Applebaum, E & Milkman, R. Leaves that pay: Employer and worker experiences with Paid Family Leave in California. 2015.
<http://cepr.net/documents/publications/paid-family-leave-1-2011.pdf>
14. United States Department of Labor, Wage and Hour Division. FMLA surveys.
<https://www.dol.gov/whd/fmla/survey/>

15. State of California, Employment Development Department. Size of Business Data - 2006 - present.
http://www.labormarketinfo.edd.ca.gov/LMID/Size_of_Business_Data.html
16. US Department of Labor Statistics. News Release - Job openings and labor turnover. May 2018. <https://www.bls.gov/news.release/pdf/jolts.pdf>
17. Golden L. Economic Policy Institute. Irregular work scheduling and its consequences. April 2015.
<http://www.epi.org/publication/irregular-work-scheduling-and-its-consequences/>
18. Wetzels M, Ruyter KD, Bloemer J. Antecedents and consequences of role stress of retail sales persons. *Journal of Retailing and Consumer Services*. 2000;7(2):65-75.
doi:10.1016/s0969-6989(99)00011-9
19. Frakt A. The high costs of not offering paid sick leave. October 2016.
<https://www.nytimes.com/2016/11/01/upshot/the-high-costs-of-not-offering-paid-sick-leave.html>
20. Ton Z. Why “good jobs” are good for retailers. January-February 2012.
<https://hbr.org/2012/01/why-good-jobs-are-good-for-retailers>
21. Tian G, Chamberlain A. The best industries for benefits: An analysis of Glassdoor benefits reviews. May 2016.
<https://www.glassdoor.com/research/studies/best-industries-for-benefits/>
22. Karpilow K. California’s paid family leave program is a national model. Shouldn’t state workers get it too? August 2017.
<https://www.sacbee.com/opinion/california-forum/article169010282.html>
23. Andrew Chang & Co. Paid Family Leave market research. December 2015.
https://www.edd.ca.gov/disability/pdf/Paid_Family_Leave_Market_Research_Report_2015.pdf
24. Field Research Corporation & California Center for Research on Women & Families.
<http://thenextgeneration.org/blog/post/new-poll-finds-just-36-percent-of-ca-voters-aware-of-paid-family-leave>
25. National Partnership. Paid Leave Works in California, New Jersey, and Rhode Island. January 2018.
<http://www.nationalpartnership.org/research-library/work-family/paid-leave/paid-leave-works-in-california-new-jersey-and-rhode-island.pdf>
26. National Conference of State Legislators. Paid Family Leave Resources. January 2018.
<http://www.ncsl.org/research/labor-and-employment/paid-family-leave-resources.aspx>
27. MacGillvary J, Firestein N. Family-Friendly Workplaces: Do Unions Make a Difference? July 2010.
<http://laborcenter.berkeley.edu/family-friendly-workplaces-do-unions-make-a-difference/>
28. Small Business Majority. About Us.
<http://www.smallbusinessmajority.org/states/california>
29. Government Alliance on Race and Equity. Who we are.
<https://www.racialequityalliance.org/>
30. State of California Department of Industrial Relations. Healthy Workplace Healthy Family Act of 2014 (AB 1522). <https://www.dir.ca.gov/DLSE/ab1522.html>

31. City and County of San Francisco. Office of Labor Standards Enforcement. Paid Sick Leave Ordinance. <https://sfgov.org/olse/paid-sick-leave-ordinance-pslo>
32. Dolan M, Khouri A. California's top court makes it more difficult for employers to classify workers as independent contractors. April 2018. <http://www.latimes.com/local/lanow/la-me-ln-independent-contract-20180430-story.html>
33. deCarufel A, Schaan J-L. Impact of compressed work weeks on policy job involvement. *Canadian Police College Journal*, 14, 2, 1990. <https://www.ncjrs.gov/App/publications/Abstract.aspx?id=125377>
34. Gajendran RS, Harrison DA. The good, the bad, and the unknown about telecommuting: Meta-analysis of psychological mediators and individual consequences. *Journal of Applied Psychology*. 2007;92(6):1524-1541. doi:10.1037/0021-9010.92.6.1524
35. Thomas LT, Ganster DC. Impact of family-supportive work variables on work-family conflict and strain: A control perspective. *Journal of Applied Psychology*. 1995;80(1):6-15. doi:10.1037/0021-9010.80.1.6
36. Yaghi N. Work flexibility and job satisfaction: The mediating role of employee empowerment. May 2016. https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1061&context=bus_admin_diss
37. Reich M, Allegretto S, Montialoux, C, Center on Wage and Employment Dynamics. Effects of a \$15 minimum wage in California and Fresno. January 2017. <http://irle.berkeley.edu/files/2017/Effects-of-a-15-Minimum-Wage-in-California-and-Fresno.pdf>
38. Jones K. The most desirable employee benefits. *Harvard Business Review*. February 2017. <https://hbr.org/2017/02/the-most-desirable-employee-benefits>
39. Roosevelt M. Parental leave expands for California workers so they can bond with their newborns. October 2017. <https://www.ocregister.com/2017/10/12/parental-leave-expands-for-california-workers-so-they-can-bond-with-their-newborns/>
40. Eisler R. Valuing and supporting the work of caregiving: A conversation with Ai-jen Poo. *Interdisciplinary Journal of Partnership Studies*. 2018: 5(1). <https://doi.org/10.24926/ijps.v5i1.1120>
41. State of California Department of Social Services. How to become an IHSS provider. <http://www.cdss.ca.gov/inforesources/IHSS/IHSS-Providers/How-to-Become-an-IHSS-Provider>
42. National Council of Women's Organizations and Center for Community Change. Explaining Social Security Benefits for Financially Vulnerable Populations. October 2013. <http://communitychange.org/wp-content/uploads/2013/10/owescccwhitepaperfinalweb.pdf>
43. Kirkham, C. California's high housing costs drive out poor, middle-income workers. January 2015. <http://www.latimes.com/business/la-fi-california-migration-20150101-story.html>

Appendices Overview

The appendices include tools we utilized to collect data, as well as summaries of the findings.

Appendix A: Key informant interview tool with a summary of findings

We interviewed 8 key informants about what they believe to be caregivers' experiences with working and caring, accessing PFL, and other employer supports. Key informants included advocacy groups, researchers, direct service providers, community organizers, public health program managers, the EDD, and an employer-advocacy group. We contacted a legislator but were unable to schedule an interview. Interviews lasted between 30 minutes and 1 hour and were audio-recorded with permission. We analyzed the transcript using thematic analysis.

Appendix B: Working family caregiver survey tool with a summary of findings

We administered a 39-item anonymous, self-administered survey electronically through SurveyMonkey and on paper, in English and Spanish. CWFC conducted outreach to organizations and caregivers to complete the survey. Approximately 933 people completed the survey, most surveys were completed electronically (n=907 or 98%). Outreach efforts were less successful at reaching caregivers who speak a language other than English, and communities of color and low-income communities. Because of insufficient numbers of people of color, we did not conduct finer data analyses. In total, we analyzed data from 924 surveys in STATA using descriptive and inferential statistics. We used chi square tests to determine statistical significance of relationships, with a significance level of 0.05.

Appendix C: Focus group tool with summary of findings

We designed (4) 1.5-2 hour focus groups with working caregivers who identified as 1) Older workers, 2) Spanish speakers, 3) Retail/service industry workers, or 4) People who used PFL. We were successful at conducting a focus group with caregivers who primarily spoke Spanish and worked in the retail/service sector. A facilitator administered the focus group in Spanish with five participants.. The audio recording of the session was transcribed and translated to English. Data were analyzed using thematic analysis. We also conducted a focus group with (3) IHSS workers.

Appendix D: Caregiver interview tool and summary of findings

We interviewed 6 caregivers with unique situations. CWFC conducted outreach to identify working caregivers who: cared for a chronically ill child, identified as Asian or Pacific Islander, identified as LGBTQ, identified as age 50+ ("older worker"), or accessed PFL. The interviews took place over telephone and lasted between 30 minutes and 1.5 hours. Interviews were recorded with permission. Data were analyzed using thematic analysis.

Appendix A: Key informant interview tool with a summary of findings

Key Informant Interview Guide

Supporting California's Working Family Caregivers

About this project

California's PFL Program allows [eligible](#) workers to take up to 6 weeks of partially paid leave from work to care for a sick family member. Research shows that caregivers are underutilizing the program, and awareness of the program's caregiving component is low, especially among low-income groups. CWFC is interested in conducting research to understand the barriers of low-income groups in accessing the program for caregiving, as well as their specific needs in providing care. Lessons from the research, conducted by HIP, will inform further research, advocacy and campaign efforts over the next three years so that low-income caregivers are better able to access resources necessary to provide care.

Your participation

Your name was provided by CWFC as someone who would add a valuable perspective to the topic of caregivers' barriers to accessing PFL and their specific needs. We appreciate your openness to providing your expertise and insights on this topic. We believe that information from you will help us better understand the issues described, as well as inform the project overall, including upcoming research with caregivers through surveys and focus groups.

About this interview

This interview will likely take place over the phone at a time convenient for you with a research staff member from HIP. The interview will take about 1 hour and will focus on the questions below. With your permission, we would like to audio record the interview to assure accurate comprehension on our part, as well as to pull quotes that could help us tell the caregiver story powerfully. Overall, your perspective will be combined with other interviewees. We will ask you to review any specific quotes or identifying details before including them in the report.

1. Why do you think there is low awareness of PFL among caregivers? Among Latino, low wage, and immigrant groups?
2. Why do you think there is low utilization of PFL among caregivers who are aware of the program? Among Latino, low wage, and immigrant groups?
3. What do you think are some barriers to utilization?
4. What (unaddressed) needs do caregivers have?
5. What (policy) recommendations or solutions do you have? (including steps that the EDD can take)
6. What other information would be useful to know to better serve caregivers? In particular, Latino, low wage, and immigrant groups?
7. What type(s) of resource or product resulting from this project would help you in your role?
8. Is there anything you would like to discuss that I may have left out?

Key Informant Interview Findings

Many working family caregivers don't know about Paid Family Leave (PFL)

Ideally, California workers would learn about Paid Family Leave (PFL) from their employer. However, advocates share that employers do not themselves understand PFL and therefore are not equipped to explain it to their workers. Employers are also not held accountable for not sharing information about PFL, which they are required to do by law.

In some work environments, human resources activities are contracted to companies outside of California - these companies may not know about or understand California workplace policies. As a result, working Californians could be misguided and/or denied of their right to take PFL. Additionally, human resources departments may not exist at all in some work environments. A stakeholder shared that low-income families and families of color tend to work in environments where a strong human resources structure is nonexistent, and as a result, many families, who are already vulnerable, do not learn about their right to PFL.

The Small Business Majority provides education and resources to small business about workplace policies and laws, including PFL. The entity is very much in support of PFL

“[Employers] are impressed and excited about PFL. It is a payroll, an employee only contribution. The biggest thing is that... it is administered through the state, so they don't have to take on that complexity, yet they still are ensuring their employee is able to take the time to either spend with a child or take care of an elderly adult or family member that needs help.” [SBM]

California's Employment Development Department (EDD) is the agency that administers PFL. Stakeholders reveal that EDD's initial efforts to increase awareness were ineffective:

“EDD had a very limited outreach campaign when law was first passed, it wasn't enough to saturate public consciousness, there has not been sustained efforts and significant resources making sure Californians know of their rights” [Advocate]

In recent years, the California Work & Family Coalition (CWFC) successfully advocated for funding to support EDD in raising awareness of PFL. In 2017, the EDD initiated a statewide campaign that included hiring a public relations firm, and increasing PFL awareness through multiple avenues including news interviews, web content, social media advertisement, ethnic media and television, and multi-language webinars. The EDD plans to carry out ongoing education and outreach even at the conclusion of the campaign in summer 2018. The EDD also plans to evaluate the impact of the campaign on PFL awareness and utilization.

Although these efforts reflect greater intention to increase PFL awareness from when the law was first passed, work and family advocates stakeholders feel that the EDD could have used funding more efficiently, for example through partnering with community organizations around California. Community organizations are not only experts in engaging with their local communities, but are trusted and accessible sources of information.

Low awareness isn't the only barrier to PFL for caregiving

Knowing about PFL does not guarantee that working caregivers will apply for the program. Both the EDD and advocates share that job instability is a concern (and a consequence) for workers and could prevent them from using PFL. Workers could face consequences at work if they take leave, including being let go, missing out on promotions, and having hours cut by employers. Stakeholders share that working caregivers even leave the workforce prematurely- as a result, they lose wages in social security benefits, retirement savings plans, and are more likely to experience poverty than non-caregivers. Workers who are low-income, women, older workers, immigrants, and work in the restaurant industry experience burdens for taking leave. Often the intersections of these groups can mean added stress.

Working caregivers, especially those who earn low wages, hesitate to take PFL because they can't take the financial risk of losing wages due to leaving work. The 60-70% compensation is not enough for many families - **"70% of minimum wage is still really really low"** - and every dollar counts toward the sustainment of hardworking families and their children. Also, job protection is not a guarantee for many workers. An advocate expresses the dilemma that many workers face: **"Why am I going to take off a few weeks but then in the long-term be unemployed long-term?"**... [Advocate]. An added layer is that wage replacement from PFL is taxed, whereas as SDI (state disability insurance) benefits are not.

Women are more likely to take on caregiving roles, and therefore, they are more likely to prematurely leave work to provide care. Low-income and middle-income women are especially vulnerable - as one respondent shared **"I've never seen a woman who makes a six figure salary quit her job to care."** Leaving the workplace, affects social security benefits, job security, skill development, and can push low-income women into poverty.

Older workers are also vulnerable, especially due to discrimination. Finding work is challenging, as a stakeholder shares, **"If you're a low income older worker, you might be easier to replace."** [Kathy, Donna]. Immigrant workers, and people who may not speak English feel especially vulnerable to retaliation in the workplace. For example, advocates shared stories of Chinese immigrant workers who are reluctant to take leave due to worry of letting down their employers.

The population of service workers, including restaurant workers has been growing tremendously in California, however laws promoting a better work environment for these workers are lacking.

"Even as these sectors are growing, there's not a growing improvement in the quality of jobs. More and more people in jobs that are low wage, minimum wage, zero job security, zero scheduling security, it's hard to have any type of caregiving responsibilities when your schedule is changing all the time" [Advocate]

The service industry also includes older workers, contrary to stereotypes, and undocumented workers too, who face added barriers taking advantage of programs that they pay into and are entitled to.

PFL was not set up to serve caregivers as it was for bonding

California's workforce has taken greater advantage of PFL for bonding than for caregiving. Usage of PFL for bonding claims has been almost ten times greater than for caregiving. Given the expected need for caregiving of the aging population, a shortage of qualifying events are unlikely to be the reason for limited use. There could be many reasons for why PFL for caregiving is

underutilized. Awareness is one reason, another is that the nature of caregiving is different from bonding.

PFL is much more effective for bonding purposes for many reasons. One being that couples readily identify being pregnant and having a timeline of when they'll need to leave work to recover and bond with their newborn. To further aid this sense of predictability, the EDD mails PFL forms to soon-to-be mothers on pregnancy disability leave. A stakeholder shares,

“There’s a natural path and EDD took advantage of it with the outreach at that moment, there’s less of a natural path ...EDD won’t know that my mother is ill, there’s no way to know, but they will know if I’m recovering from delivering a child from using SDI, I’m looking at bonding with that child as well.” [Advocate]

Contrarily, caregiving duties can be unpredictable, intermittent, and long-term. People likely don't think about PFL until they need to, when a crisis happens, and crises are often not planned. A respondent shares that during these times, PFL isn't the first thing, or even the second thing, that caregivers think about:

“often caregiving issues arise suddenly, and you just do what you need to be there for your family, and a benefit program like this can be secondary especially if it's complicated and difficult to navigate” [Advocate]

Additionally, doctors and other health care providers are more accustomed to providing guidance to expecting parents and completing forms for pregnancy and bonding-related leave from work. Understanding the relevance of PFL for working caregivers requires more initiative and knowledge on the part of the provider, which is lacking in comparison - there just isn't good guidance all around for navigating PFL for caregiving needs.

Caregiving situations can be complex and unique from bonding, and vary from person to person, which is why employers and state agencies should create and support flexible leave policies that serve caregivers and their individual situations.

Improvement to PFL is happening, but change is slow

Many working caregivers might learn about their right to PFL and seek to access it, but could face additional barriers in actually benefiting from it. Stakeholders reveal that administrative barriers with implementation of PFL are just **“not worth the effort”** for already overwhelmed working caregivers and if **“there are too many barriers, people not going to use it.”** Advocates identify hassles such as not being able to get through the phone, accessing application material (and in a preferred language), and having claims rejected due to minor errors. EDD staff acknowledge issues with PFL implementation, and are addressing concerns, and implementing solutions, **“we’re really hoping that the pain points we see today, we will not see with the implementation of that system”** [EDD]

Advocates expressed a number of frustrations, including with being able to speak with someone on the phone through EDD.

“If you actually call the EDD hotline, the phone number, you literally usually cannot talk to anyone.... I’ve called upwards of ten times. And number one no one answers the phone, number number two, there’s no way to leave a voicemail and a lot of times you’ll go to ringing for awhile. It’ll go to an automatic voicemail saying, you’ve

reached the maximum number of people who can wait on the line. Goodbye”
[Advocate]

The EDD is addressing call volumes by implementing a telephone system that allows callers to determine and select options relevant for them, and the option to receive a call from the EDD when it is their turn to speak to an agent. The agency points to challenges such as system and resource constraints and hopes to implement a system where users do not need to call in, unless they really need to.

“We have over 17 million Californians who pay into this program. I will tell you from a call center perspective, we probably get 4 million plus calls every year, we probably answer 1 million plus. So even though we’re doing our very best with the resource levels that we have, we will ever have enough resources to answer a million calls? Probably not. But what we can do, is we can better utilize technology so that we can provide a better customer experience.” [EDD]

Another source of frustration is that application and educational material is not easily accessible. The application can be challenging to fill out for someone who has a low-literacy level and feels uncomfortable with English. This leaves people feeling embarrassed. Advocates also reveal that material for non-English speakers is not in enough second languages and is not translated well (if it is translated). As a result, communities can face difficulty making sense of valuable information, even if it is in their own language. An informant summarizes the unique experiences of Latino and immigrant workers:

“The challenges for those groups are just magnified because often materials coming out of the agencies are not in own language or are not easily accessible, and often those are workers who feel already quite vulnerable in their jobs.” [Advocate]

EDD staff expressed the importance of language accessibility and provides services in 9 languages total, including a language access plan. EDD reports having an accessibility workgroup to address barriers to access, as well as staff who continuously working on improvement application forms.

“In terms of our commitment to serving a diverse population who really has a need, and diverse languages we are really on top of that and we are really proud of our work in that area” [EDD]

Many advocates point to how PFL is complicated to use for intermittent leave. Often times, working family caregivers may need a day or few days off over several months, for example to care for a loved one who is going through cancer treatment.

“Some of the caregiving responsibilities...more like where it isn’t long blocks of hours, it’s just needing time to having to pick up medicines, going to doctors appts that could be a 2 or 3 hour thing once a month, twice a month, but if you don’t have the flexibility, then the person you’re caring for could miss a vital check up or followup, or a criss happens, they get a UTI, they need to go to the doctor, and somebody needs to accompany them” [Advocate]

To address this, the EDD has developed a special form for intermittent leave and has eliminated a waiting period between days that caregivers need to be able to provide assistance.

While advocates shared a number of frustrations, the EDD cited customer experience surveys that overall indicate satisfaction. This discrepancy could be due to many reasons, including the (planned)

PFL improvements have not yet reached users, or customer satisfaction focuses on specific outcomes, or concerns stem from an overwhelmingly negative sample of customers who report frustration compared to those who had no or few complaints.

“We survey our customers every year. We do a large survey... I want to say there’s a very high percentage, some cases 60-70%, some cases 70-80% who responded saying they that were very pleased with our service, they were very pleased with the responses they received online, they were pleased with their customer experience. So we know we are making some improvements” [EDD]

Sadly, it is not uncommon for caregivers to submit applications and be rejected - even when their claims are valid. The various pieces of information required for the application can be confusing, including matching paperwork from doctors and benefits information from employers.

“My concern is that there are a lot of barriers to a person finding out about and then applying for PFL for their caregiving needs, and if they go through all of that and we actually get them to make contact with EDD and ask for the benefits , that we don’t reject people with valid claims. “Gosh, when we finally do get somebody with a legitimate claim to file that they don’t then get a rejection letter and then have to jump through all these other hoops to appeal it, that EDD look at ways to improve the success for caregivers applying for [PFL].” [Advocate]

Work and family advocates and PFL administrators have developed a strong working relationship that can benefit from deeper communication about concerns with PFL and addressing them. Ongoing collaboration between these stakeholders is vital, and can help to continuously improve PFL implementation.

Improving PFL is not enough to support working family caregivers

To address PFL exclusively would be a siloed approach in supporting working family caregivers. Californians who work and care do so in the context of other related workplace policies. Advocates expressed concern that EDD’s exclusive focus on PFL can be ineffective for caregivers who need to take into account FMLA, CFRA and other laws to understand their comprehensive rights. Many stakeholders shared that differing requirements of the many laws (PFL, FMLA, CFRA) creates a lot of confusion for working caregivers in understanding what they are entitled to.

“Family leave issues are actually quite complex, and when we talk about paid family leave, that’s not the only thing you need to know... so people might have heard about the FMLA, or they might have heard about PFL, but they don’t really know which is which or what each one does in relation to the other. I think one of the most difficult thing about patchwork of laws, is that it’s not simple, you actually have to be aware of a number of different programs and laws in order to have the full picture of what your rights are.” [Advocate]

Informants shared that the EDD is hesitant to bring up FMLA or CFRA because they don’t administer it and are not the expert. The EDD will instead refer caregivers to other agencies to figure it out. As a result, advocacy agencies are spending as much as 15-20 minutes on individualized counseling sessions, with each caregiver to discuss their unique situation, rights and navigating the application processes.

Advocates shared that the EDD also does not share important information about protecting workers from retaliation from their employers. As one an informant shares, **“Even asking your HR person**

(if you're lucky to have one) about rights like PFL can be a risky thing." Knowing that a law protects them may help working caregivers feel more confident in talking with their employers about taking family leave. Stakeholders express that the EDD should integrate more closely with the Division of Labor Standards to better enforce retaliation laws and hold employers accountable. Because this handling of retaliation is done through a different agency, EDD is less inclined to provide this information to caregivers.

Informants shared that working caregivers don't care which agency has territory over which program or policy, they just need to know enough to weigh the pros and cons of pursuing leave --**"I don't want to just to know what I have a right to. I want to know like how is this actually going to work when I run into problems"**

Alternative solutions do exist, but they are not universally available to all working caregivers. When working family caregivers are not using PFL, they are using sick leave and vacation time from their employer. Other workplace flexibility options, such as working from home, working night shifts and modified hours, if available, are often used:

"The people are figuring out how to fill in the gaps. They working 4 10s so that they can be there on Friday, or working the nightshift because the family member who is dying of cancer is sleeping through the night mostly but during the day they need to be there, they're doing whatever is. People are finding a way to bridge the gap"

[Advocate]

Unfortunately, in the absence of accommodating, flexible and predictable work schedules, many workers will struggle to find solutions: **"If you're lucky enough be an employee who has sick or vacation time, not accessing this [PFL] isn't as great of a burden on you as someone who has no alternatives."** PFL could be a viable solution, but sadly, is not accessible to low-wage workers. As a result, workers may ask other family members to help, or turn to already limited community resources. In worst case situations, workers will leave their jobs which has its own consequences:

"What I've seen ... is that if the person needs the care, they need the care, a lot of times the workers are just forced to leave their job...if work does not accommodate taking off time, then I've seen people leave work for short periods of time, 6 months or fewer at a time." [Advocate]

Although there is a demand of jobs in sectors like the service industry, finding work again can be disruptive considering the length of time without a source of income, time required to job search, and having less seniority for selecting hours because they have to **"start from scratch"**.

A holistic solution to serving family caregivers includes not only access to PFL but alternative solutions, such as support and flexibility from employers.

Recommendations include increasing PFL awareness and addressing program barriers

Policymakers must adopt comprehensive means to support working family caregivers. One of the most important endeavors is making sure that workers who provide care are financially stable. Changes must happen on many levels for PFL and other workplace policies to be effective - at the EDD, with employers, with ally settings, and culturally across communities in California. PFL has the potential to relieve **"one of the many aspect of stress"** related to caregiving, but only if it is accessible and equitable.

Awareness efforts should be community-driven, cross-sector, and comprehensive

A lot of work needs to go into seeing that people are aware of PFL. Many advocates shared that there is a lack of leadership in distributing information about PFL. However, this is likely because the EDD's outreach campaigns are only recent and may not have yet reached critical mass around the state.

Community-driven

Advocates have specific ideas for increasing awareness and the EDD, employer community and other stakeholders should work together to see that efforts are grounded in community experience. Advocates propose that the EDD work in close partnership with local community organizations to carry out some of these educational efforts. State agencies should provide funds to these groups who have strong expertise and trust with different communities.

“If you bring it to the statewide level, it’s a little harder to really increase the message, but when you bring it into the local level, it just expands, and it doesn’t take much either” [Advocate]

Educational efforts should be mindful of language and terminology - caregivers don't always identify themselves to be caregivers but may identify with alternative verbiage. There is misconception about PFL being government assistance - efforts should address stigma and emphasize that California workers pay into the program.

Material in languages other than English should be tested with community members to see that translation makes sense. Research should be invested in seeing what communication methods are effective for the different communities and for hard to reach populations such as those with chronic conditions and disabilities, the elderly, and undocumented workers. A community advocate shares the unique experiences of undocumented workers who are eligible for PFL:

“Undocumented workers have a lot of questions about whether or not they qualify to take PFL and so as long as you pay into short term disability insurance you should be able to access that money but the combination of not being sure of whether or not they qualify, and also the general immigration climate, a lot of immigrants are fearful of having any type of interaction with government agencies.” [Advocate]

Cross-sector

PFL and other family leave policies may not be normalized for employers and so employers require some training on these topics. Ongoing education with human resources professionals can help employers be more sensitive to workers' needs and more proactive, responsive, and knowledgeable about providing access to policies.

“If employers don’t have good HR practices in place to accommodate people have fluctuations in family responsibilities, it will be harder to run the business, temporarily, due to employer unfamiliarity.” [Advocate]

To identify the employment setting as the primary place for people to learn about PFL could be limiting. Stakeholders shared that other settings where caregivers are likely to engage should be providing information about PFL.

The healthcare delivery setting is a regular point of contact for caregivers, especially as they support care recipients with their medical needs. Some clinics have already integrated PFL education and application support into their clinical protocols, such as in prenatal care, whereas others are

exploring the possibility, such as through a patient discharge plan. Limited resources at clinics, such as time and personnel to provide education are barriers however, but can be addressed through grant funding.

Other settings include places that families go to often - churches, schools, and community colleges. The EDD is looking into the DMV as site for sharing information about PFL.

Comprehensive

PFL education must include information about job protection and protection from retaliation. Given the confusion and many questions working caregivers have about job protection, any education about PFL should also include details about right to job protection, specifically, if workers qualify for family leave laws such as FMLA and CFRA. Workers also need to understand that, if they are eligible for job protection, that employers cannot fire them for taking family leave. Having this information may influence whether or not workers are willing to take leave.

Advocates shared that language on consequences for employers is not strong in PFL outreach material and should be emphasized ... **“even if you as an employer don’t like policy, you need to understand how you’re legally obligated and liable if don’t follow it”** [Advocate]

Working family caregivers need more than PFL

Workplace supports

Advocates agreed that support from the work environment means scheduling flexibility. Flexibility includes adjustment to a schedule, transferring to a location closer to the care recipient, working from home or remotely. Working family caregivers also need predictable work schedules, especially those in the retail and service industry. Having options means that workers have more to work with while they try to coordinate responsibilities of work, and care.

A long-term goal is assuring that working caregivers fall under a protected class. Doing so will emphasize that discrimination and retaliation against working caregivers is against the law, and that employers should be accommodating of their needs. Workers under disability are eligible for workplace accommodations. Pregnant women and new parents are also able to receive workplace accommodations under law. Policies for these workers can serve as models for working caregivers who also need workplace flexibility and support. Advocates point to a “huge gap” in workplace policies serving working family caregivers.

Job protection and full wage compensation

The overwhelming concerns with PFL are that it does not include job protection and the wage compensation is not enough. These are leading reasons for why working family caregivers are not using PFL, according to stakeholders.

Also, the types of family relationships that qualify are limited. African American, Latino and other communities of color often care for extended family members such as aunts, uncles, cousins, and close family friends or where strong ties exist. Public sector and contractor employees are left out of PFL. Also, policymakers should consider what amount of leave is adequate. Some states have paid leave available for up to 12 weeks.

Supplemental benefits

Consequences such as shorter hours or loss of wages from lack of promotions means that working caregivers probably aren't financially stable. If they leave the workplace, they do not accrue social security and lose access to health insurance and employer-supported retirement savings programs. To fill in these gaps, care providers should have resources that will allow them to save for their future. Solutions include health care waivers, supplemental income.

Other supports

Support for working family caregivers should go beyond workplace policies. This includes providing emotional support through support groups and counseling, especially during the first year of providing care. Caregivers have their own health needs and stressors, which is why financial stability and having reliable health insurance and supplemental income is important. Training and education for how to provide care, as well as "care agreements" between family members can also alleviate burdens involved with caregiving.

Caregivers who are caring for seriously ill parents, grandparents, and their children are described as the "sandwich generation." Stakeholders expressed the significant challenges that caregivers of the sandwich generation face. This community often has to "figure it out" alone.

We must continue fighting for working family caregivers

On a broader cultural scale, we as a society need to change the way we talk about caregiving. Advocates share that a greater valuation of caregiving responsibilities can help move policies further just as they have for bonding. Because caregiving can be long-term, we need to think beyond 6 weeks or 12 weeks of support for working caregivers. Change is needed in the workplace, as well as the social services sector to build a sustainable system that includes flexibility or family caregivers, larger and better trained allied care workers.

Also, communities should be empowered to mobilize and demand rights to access policies, and community and government agencies should partner with them to do. as one community organizer states, **"there needs to be critical masses, people within immigrant service, low wage industries, taking a lead for these types of leave to normalize."** [Advocate]

The ineffectiveness of PFL has consequences, not just for the hardworking family caregivers who are trying to find ways to accommodate work and care responsibilities, but all of us. More often than not, all of us will find ourselves in a position to provide care to a loved one. The right thing to do is to make family leave policies comprehensive and equitable for all Californians.

"Family caregivers are not aware of PFL and therefore are leaving the job market prematurely, and therefore we're losing vital workers and we're also straining our health care system because these workers don't have insurance, they're more likely to go into poverty, once they lose their job, they're also not having money toward retirement, and so they're retirement and savings is also lower and all of this means that we're putting a larger strain on our public services ... Paid family leave helps help keep people in the homes in the community and out of long term care institutions... The more that you can support paid working caregivers, overall, there is a huge-cost savings to the State." [Advocate]

Appendix B: Working family caregiver survey tool with a summary of findings

Survey

Supporting California's Working Family Caregivers

The [California Work & Family Coalition](#) and [Human Impact Partners](#) are working on a project about state and workplace policies for people who work and assist family members and friends with serious health conditions. This survey will help advocates *and* policymakers understand what these caregivers need so they can campaign for change. Please read the [project information sheet](#) for more information

---To participate in this survey, you must answer YES to both #1 and #2---

#1. In the past 12 months, have you provided **SUPPORT OR CARE** to a family member, friend or other loved one with a **SERIOUS HEALTH CONDITION**

Yes No. *If no, please do not complete this survey*

Examples of support/care

- Taking family member to medical appointments
- Ordering and/or picking up and/or helping to administer prescription medications
- Preparing meals and/or grocery shopping
- Providing psychological comfort and care
- Making arrangements for changes in care

Examples of serious health conditions

- Illness, injury, surgery, impairment, physical or mental condition that requires hospital stay or overnight admission
- Chronic conditions requiring periodic medical visits including asthma, diabetes, epilepsy, migraine, and disability
- Permanent and long-term conditions such as Alzheimer's, dementia, stroke, and terminal illness
- Conditions requiring multiple and continuing treatments including cancer, severe arthritis, kidney disease, and physical therapy
- Treatment for substance abuse and mental health conditions such as depression, anxiety, and post-traumatic stress disorder (PTSD) from referral by health provider

Types of family members and friends

- Your spouse, partner, sibling, cousin, parent, parent-in-law, aunt, uncle, grandparent, grandchild, child, niece, nephew, friend, neighbor, extended or chosen family

#2. During this time were you **EMPLOYED OR WORKING AT ALL**? *If you are getting paid to take care of your family member or friend, please do not fill out this survey.*

Yes No. *If no, please do not complete the survey*

---If you answered YES to both #1 and #2, please continue

This survey is confidential: We will not share the completed surveys with anyone. Please do not write your name anywhere on the survey. This survey has 39 questions and takes 10-20 minutes to complete depending on your responses. Please give the completed survey back to the study

coordinator when you are done. Please read the [project information sheet](#) for project and contact information, and resources. We appreciate your time in taking this survey. Thank you for participating!

About your employment

1. How many different jobs do you work? _____(Specify number)

2. What sector(s) do you work in? (Select **all** that apply)

- I work in the private sector (i.e., business, corporation)
- I work in the public sector (i.e., government, public school or university)
- I work for a non-profit
- I am a contractor
- I am self-employed
- Other: _____

3. What industry do you work in? (Select **all** that apply)

<input type="checkbox"/> Hotel, food services	<input type="checkbox"/> Manufacturing
<input type="checkbox"/> Farming, forestry, fishing, and hunting	<input type="checkbox"/> Public administration
<input type="checkbox"/> Arts, entertainment and recreation	<input type="checkbox"/> Real estate
<input type="checkbox"/> Construction	<input type="checkbox"/> Retail
<input type="checkbox"/> Education	<input type="checkbox"/> Transportation
<input type="checkbox"/> Finance and insurance	<input type="checkbox"/> Utilities
<input type="checkbox"/> Health care	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Social services	

4. How long have you worked at your primary (where you work the most hours) employer?
_____ (Specify days, months, or years)

5. How many people, including yourself, work within 75 miles of your workplace, for your primary employer?

- 1-10 people
- 11-19 people
- 20-49 people
- 50 or more people
- I don't know

6. How many hours per week do you typically work for your primary employer?

- 1-20 hours
- 21-25 hours
- 26-30 hours
- 31-40 hours
- More than 40 hours. Specify: _____
- It varies every week

7. What is your hourly wage at your primary employer? (NOTE: if you are salaried, please estimate)

- \$00.00 - \$10.50 [up to \$21k, if full-time]
- \$10.51 - \$13.99 [about \$22-28k, if full-time]
- \$14.00 - \$19.99 [about \$29-40k, if full-time]
- \$20.00 - \$29.99 [about \$41-60k, if full-time]
- \$30 or more [about \$61k or more, if full-time]

8. Do you typically know your work schedule 1-2 weeks in advance at your primary job?

- No
- Yes

9. How often does your work schedule change during the work week at your primary job?

- Always
- Often
- Sometimes
- Rarely
- Never

10. Do you have a choice or say in creating your work schedule at your primary job?

- Always
- Often
- Sometimes
- Rarely
- Never

11. Does your primary employer provide paid time off (i.e., sick days, vacation days, or paid time off (PTO))?

- No
- Yes. Specify days per year if known: _____
- I don't know

12. Do you have the option to work from home if needed at your primary job?

- No
- Yes
- I don't know

13. Does your primary employer offer health benefits?

- No
- Yes
- I don't know

14. Does your primary employer offer a retirement plan (i.e., 401(k), 403(b)) or pension)?

- No
- Yes
- I don't know

15. Does your primary employer offer paid family leave benefits?

- No
- Yes
- I don't know

16. Have you ever taken time off of work (at your primary job) to care for or support a family member or friend with a serious health condition?

- No
- Yes

16a. What type of time off did you take off work? (Select **all** that apply)

- Vacation time
- Sick time
- Other paid time off (PTO)
- Unpaid time off
- Schedule change
- Other_____

16b. If you took PTO, vacation time, or sick time, would you have wanted to request a schedule change instead?

- No
- Yes
- I did not take PTO, vacation time, or sick time
- My schedule is not flexible

16c. How easy was it to take time off from your primary employer to care for or support your family member or friend?

- Very easy
- Somewhat easy
- Somewhat challenging
- Very challenging
- Impossible

About California's "Paid Family Leave" for Caregiving

17. Have you heard of the California "Paid Family Leave" program?

- No. **If no, continue to 25**
- Yes

17a. If yes to #17, where did you first learn about “Paid Family Leave”? (Select **all** that apply)

- My current or former employer or human resources department at work
- A family member or friend
- A community organization. Specify name if you remember:

- My union. Specify union if you remember: _____
- A doctor or other healthcare provider
- The California Employment Development Department (EDD)
- The Internet. Specify the website if you remember:

- Other: _____

17b. Did the person/resource explaining “Paid Family Leave” do a good job explaining it?

- No
- Yes

18. Was it easy to understand whether you were eligible for California “Paid Family Leave” for caregiving purposes?

- No
- Yes

19. Do you understand California “Paid Family Leave” well enough to explain it to someone else?

- No
- Yes

20. Do you know anyone who used “Paid Family Leave” for caregiving?

- No
- Yes

21. Have you ever applied for California “Paid Family Leave” for caregiving purposes?

NOTE: This program is only available if you are caring for a: parent, parent-in-law, grandparent, spouse, registered domestic partner, sibling, or child. Also, most public sector employees and contractors are not eligible.

- No
- Yes
- I don’t know

21a. If yes to question 21, how many times have you applied for “Paid Family Leave” for caregiving purposes in the past 12 months? _____

21b. If yes to question 21, have you ever successfully received claims or compensation from “Paid Family Leave” for caregiving purposes?

- No
- Yes

22. What challenges or barriers have you experienced when you applied for or considered applying for “Paid Family Leave” for caregiving purposes? *Please read **all** options and select **all** that apply*

- I haven’t considered applying for “Paid Family Leave”
- I haven’t experienced any problems when using “Paid Family Leave”
- I didn’t think I qualified or was eligible for “Paid Family Leave”
- I don’t consider myself a caregiver
- My family member’s health is not serious enough
- I have other resources (people) to care for my family member
- I used sick time or vacation time or paid time off to provide care
- I work part-time and have time to care for my family member
- I work from home (sometimes) and have flexibility to provide care
- My employer gives me flexibility to balance providing care
- I do not have reliable access to the Internet
- I do not work in California
- Other (specify): _____

23. What ADDITIONAL challenges or barriers have you experienced when you applied for or considered applying for “Paid Family Leave” for caregiving purposes? *Please read **all** options and select **all** that apply*

- I haven’t considered applying for “Paid Family Leave”
- I don’t want to or like to use government assistance
- I don’t trust the government
- I don’t feel comfortable providing my personal information to the government
- I do not want to share my family member’s health information
- My employer did not support me in using it
- I fear what my employer may think or do if I use “Paid Family Leave”
- I fear not having a job when I return from leave
- I can’t afford to lose some of my wages
- I tried calling the Employment Development Department but could not get through
- The Employment Development Department staff were not helpful
- I don’t speak or read English well/the application is not in my language
- The application process is too confusing or complicated
- The application process takes too much time
- Applying for intermittent or temporary leave is a hassle
- There is too much paperwork
- Other (specify): _____

24. If you have not used “Paid Family Leave” for caregiving, what would make it easier to use it?

- Guarantee my job is protected when I leave
- More wage compensation
- Better application process
- Something else (specify): _____

About your family member or friend with a serious health condition

Please answer the following questions for *each* family member or friend (with a serious health condition) for whom you provided support or care anytime in the past 12 months. If you provided support/care for *one* family member or friend, please fill in the first column only.

25. What is your relationship to the family member/friend you have provided support/care for? (in other words, who are you caring for?)

Family/friend #1	Family/friend #2	Family/friend #3	Family/friend #4
<input type="checkbox"/> Partner or spouse <input type="checkbox"/> Child <input type="checkbox"/> Sibling <input type="checkbox"/> Parent <input type="checkbox"/> Parent-in-law <input type="checkbox"/> Grandparent <input type="checkbox"/> Grandchild <input type="checkbox"/> Friend <input type="checkbox"/> Other: _____ ____	<input type="checkbox"/> Partner or spouse <input type="checkbox"/> Child <input type="checkbox"/> Sibling <input type="checkbox"/> Parent <input type="checkbox"/> Parent-in-law <input type="checkbox"/> Grandparent <input type="checkbox"/> Grandchild <input type="checkbox"/> Friend <input type="checkbox"/> Other: _____ ____	<input type="checkbox"/> Partner or spouse <input type="checkbox"/> Child <input type="checkbox"/> Sibling <input type="checkbox"/> Parent <input type="checkbox"/> Parent-in-law <input type="checkbox"/> Grandparent <input type="checkbox"/> Grandchild <input type="checkbox"/> Friend <input type="checkbox"/> Other: _____ ____	<input type="checkbox"/> Partner or spouse <input type="checkbox"/> Child <input type="checkbox"/> Sibling <input type="checkbox"/> Parent <input type="checkbox"/> Parent-in-law <input type="checkbox"/> Grandparent <input type="checkbox"/> Grandchild <input type="checkbox"/> Friend <input type="checkbox"/> Other: _____ ____

26. Are you the person who provided the most support/care for this family member/friend?

Family/friend #1	Family/friend #2	Family/friend #3	Family/friend #4
<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes

27. How many hours per week (on average) did you provide support/care to this family member/friend? (this includes transportation, meals, medicine, comfort, etc.)

Family/friend #1	Family/friend #2	Family/friend #3	Family/friend #4
_____hours/week	_____hours/week	_____hours/week	_____hours/week

28. How long have you provided support/care to this family member/friend?

Family/friend #1	Family/friend #2	Family/friend #3	Family/friend #4
_____ (Circle: weeks/months/years)	_____ (Circle: weeks/months/years)	_____ (Circle: weeks/months/years)	_____ (Circle: weeks/months/years)

29. Did you live with this family member/friend when you provided care/support?

Family/friend #1	Family/friend #2	Family/friend #3	Family/friend #4
<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes	<input type="checkbox"/> No <input type="checkbox"/> Yes

<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Sometimes
------------------------------------	------------------------------------	------------------------------------	------------------------------------

About you

30. What is your zip code? _____

31. What year were you born?_____

32. What is your gender?

- Female
- Male
- Trans Woman
- Trans Man
- Gender Non-Conforming
- Gender Fluid
- Option not listed: _____
- Decline to state

33. Regarding sexual orientation and/or gender that you are attracted to, do you consider yourself to be: *(Note: We welcome and affirm any and all LGBTQ identities)*

- Heterosexual or straight
- Gay or Lesbian
- Bisexual
- Option not listed: _____
- Decline to state

34. What is your race/ethnicity? (Select **all** that apply)

- Non-Hispanic White
- Black/African-American
- Native American/Alaska Native
- Latin(a/o)/Hispanic
- Asian/Pacific Islander
- Other or specify race/ethnicity: _____
- Decline to state

35. What is the highest level of education you have completed?

- Up to high school
- High school diploma or GED
- College - Associate degree
- College - Bachelor's degree or more
- Decline to state

36. What is your annual household income? (This includes everyone who lives in your household and contributes to expenses)

- \$0 - \$44,999
- \$45,000-\$49,999
- \$50,000-\$59,999
- \$60,000 or more

- Decline to state

37. What language do you prefer to speak in? (Select **all** that apply)

- English
- Spanish
- Cantonese
- Mandarin
- Tagalog
- Vietnamese
- Korean
- Other: _____
- Decline to state

38. (Optional) Is there anything else you'd like us to know

39. (Optional) We are looking for people to share their stories about caregiving in future campaign efforts. Would you like to participate?

- Yes, I am interested in sharing my story.
If yes, please contact the California Work & Family Coalition at **info@workfamilyca.org** or **(510) 473-2216**. This contact information is also on the project handout.
- No, I am not interested in sharing my story

Survey Findings

PART 1: Caregivers and their care + work experiences

Who are the working caregivers (survey participants)?

The typical survey respondent is an older, high income earning, educated, white female. On average, participants were 58 years old. The majority of participants were heterosexual (93%) and female (78%). Whites made up the majority (64%) and, Latinx were a far second at 14%. About 54% of participants had a bachelor's degree or higher and most, about 61% had an annual household income of \$60k or greater.

What are workplace characteristics of working caregivers?

Working caregivers work an average of 1.3 jobs and the majority have 1 job (77%). Most respondents work in the private sector (48%), followed by public (27%), nonprofit (14%), contract (6%), self-employment (17%). With 62% of participants working in private and non-profit sectors, the majority of survey takers are eligible for California Paid Family Leave. PFL eligibility prevalence could be greater if workers or their employers from other sectors opt to pay into the State Disability Insurance program on their payroll taxes.

The health (23%) and education (16%) industries were leading industries among participants. A substantial proportion of survey takers (up to 25%) listed "other". When exploring self-reported industries, many participants can be classified into the "professional" sector or the "other sector". These designations are used by California's Employment Development Department (EDD) and can be limited and confusing for the general public as was likely the case on this survey.

A substantial number of participants work in an environment with 50+ employees (40%), and in places with 1-10 people (25%). Interestingly, more than 1 in 5 don't know how many people work in their workplace (22%). Caregivers have worked at their jobs for an average of 13 years, plus or minus 10 years standard deviation. Most workers skew toward worker in their positions for fewer years, for example, about 10% of workers have been in their current roles for 1 year or less. The data on employee size and tenure tells us that a substantial portion of people completing the survey are not eligible for FMLA and therefore California PFL could potentially be the only government-based family leave program they would be allowed to take.

Most people work about full-time 31-40 hours/week (52%), a substantial proportion work more than 40 hours/week (22%). Participants who work part-time could have had to reduce their hours due to caregiving needs. This was frequently mentioned in the comments section. Some participants also indicated having to retire prematurely. A substantial proportion of survey takers earn \$30/hr or more (47%), followed by \$20-\$29.99 (25%). Almost a third earn below \$20/hr (28%).

Who are caregivers caring for?

Almost half (47%) of working caregivers are caring for a parent, followed by a partner or spouse (29%). Fewer are caring for their child (10%) or other friend or family member (7%). These other types of relationships, which PFL does not cover included fiances, aunts, nephews, cousins.

The majority of participant are caring for one person (82%) although almost 1 in 5 are caring for 2+ family member or friend (18%). Most are also the primary caregivers (87%) and 2 of 3 live with their loved one (67%). Time spent caring can be comparable to have a full-time job (outside of paid work) with working caregivers spending an average of 36 hours/week on care. The length of time on care is an average of 5.2 years.

What workplace supports and benefits do people have?

As a whole, caregivers seem to have good workplace supports and benefits with the exception of working from home, which is limited to 32% of working caregivers.

- 84% know their work schedule in advance
- 66% of people rarely or never experience schedule change during the week
- 67% sometimes, often or always have a say in creating their work schedule
- 74% of people's employers offer PTO, and health benefits

The likelihood that employers offer a retirement plan (67%) and paid leave benefit (45%) is lower. The prevalence of employer-provided paid leave is higher than expected and may be a result of confusion about types of time off. About 16% of caregivers did not know whether their employers offered a paid leave benefit.

What was the experience of taking time off to care?

Most (84%) took time off of work to care. Most people used sick time (42%), followed by vacation time (36%). A substantial proportion of people took unpaid time off (37%). Although most caregivers indicated that it was not challenging to take time off work to care (59%), a substantial proportion (41%) said it was somewhat challenging, very challenging or impossible.

How challenging was it to take time off for people with different workplace supports and benefits?

People who have schedule predictability have an easier time taking time off work to care (61% vs. 51%, $p=0.03$). People who have fewer changes to their schedule have an easier time taking time off to care (66% vs. 51%, $p<0.001$). For people who worked more jobs, it was harder to take time off (51% vs. 38%, $p=0.001$). People who have PTO have an easier time taking time off of work to care (62% vs. 53%, $p=0.03$). People who have employer provided paid leave have an easier time taking time off to care (69% vs. 50%, $p<0.001$).

People in the public sector have an easier time taking time off to care (66% vs. 57%, $p=0.02$); also - people working in public administration (75% vs. 58%, $p=0.01$). Retail workers tend to have a more challenging time ($p=0.002$) although the sample size of retail workers was small.

PART 2: Distribution of workplace supports and benefits

How do workplace supports differ for people from different sectors, industries, workplace characteristics, demographics?

Sectors

Caregivers working in the private sectors were more likely to have health benefits (80% vs. 70%, $p=0.001$), PTO (83% vs. 68%, $p<0.001$), paid leave from employer (51% vs. 43% $p=0.02$). Those in the public sector were more likely to have most workplace supports ($p<0.001$) including predictability (93% vs. 81%), PTO (89%, 70%), health benefits (90% vs 69%), retirement (88% vs.

63%), paid leave from their employer (60% vs. 42%), but less consistency (34% vs. 48%), authority (53% vs 73%). Those in the nonprofit sector have greater schedule authority (76% vs 66%, $p=0.02$), and report having PTO (83% vs. 74%, $p=0.03$).

Contractors have overall less workplace supports including less predictability (69% vs 85%, $p=0.002$), PTO (24% vs 78%, $p<0.001$), health benefits (39% vs. 77%, $p<0.001$), retirement (35% vs 72%, $p<0.001$), employer paid leave (15% vs. 49%, $p<0.001$). They did have more consistency (67% vs 43%, $p<0.001$), authority (83% vs 66%, $p=0.02$).

Those who are self-employed also had unique workplace benefits. They had less schedule predictability (61% vs 89%, $p<0.001$), greater inconsistency (72% vs 38%, $p<0.001$), greater authority (87% vs 63%, $p<0.001$), but fewer supports like having PTO (24% vs 86%, $p<0.001$), health benefits (27% vs 84%, $p<0.001$), retirement benefits (21% vs 80%, $p<0.001$), employer provided paid leave (9% vs. 56%, $p<0.001$)

Industries

Those working in the hotel industry were less likely to report health benefits (58% vs 75%, $p=0.03$) a retirement plan (48% vs 70%, $p=0.04$), employer provided paid leave (4% vs. 48%, $p<0.001$)*. Arts/recreation workers also had fewer supports including, employer-provided paid leave (20% vs 49%, $p<0.001$), retirement plan (42% vs 71%, $p<0.001$) health benefits (44% vs 77%, $p<0.001$), PTO (40% vs 78%, $p<0.001$), schedule inconsistency (60% vs 43%, $p<0.01$). Construction workers were less likely to have PTO (31% vs 77%, $p<0.001$), health benefits (48% vs 75%, $p=0.001$), retirement benefits (31% vs 71%, $p<0.001$), employer provided paid leave (11% vs 48%, $p<0.001$)*

Those working in education had less schedule authority than other sectors (60% vs 69%, $p=0.03$). Those in the health field had greater schedule predictability (89% vs 83%, $p=0.02$). Those in the social services field had greater predictability as well (92% vs 83%, $p=0.03$)*Those in manufacturing were less likely to have schedule authority (53% vs 68%, $p=0.02$) but more likely to have health benefits (86% vs 74%, $p=0.03$)*. Public administration employees had greater workplace supports, including schedule predictability (94% vs 84%, $p=0.04$), PTO (95% vs 74%, $p<0.01$), health benefits (95% vs 73%, $p<0.001$), retirement plans (94% vs. 68%, $p<0.001$), employer provided PFL (67% vs. 45%, $=0.001$). Those in real estate were less likely to have PTO (76% vs 54%, $p=0.009$), and less likely to have schedule predictability (58% vs 85%, $p<0.001$). Those in transportation are less likely to have schedule authority (51% vs 68%, $p=0.04$)

Workplace characteristics

All workplace supports were related to workplace size. Less schedule inconsistency ($p<0.001$), and greater predictability ($p<0.001$), PTO ($p<0.001$), health benefits ($p<0.001$), retirement plan ($p<0.001$), employer-provided PFL ($p<0.001$) were more prevalent in environments of 50+ employees vs. smaller organizations in a graded manner. The exception being that smaller organizations have greater schedule authority ($p=0.009$).

Hourly wage was also associated with workplace supports. Those with higher wages had less schedule inconsistency ($p<0.001$), and greater predictability ($p<0.001$), schedule authority ($p=0.003$), PTO ($p<0.001$), health benefits ($p<0.001$), retirement plan ($p<0.001$), employer-provided PFL ($p<0.001$). Work environments with more employees tend to have higher wages, $p<0.001$).

Demographics

People who were older had greater schedule authority (75% vs 64%, $p=0.001$), but less likely to have PTO (70% vs. 80%, $p=0.003$), health benefits (69% vs. 79%, $p=0.002$), retirement plan (63% vs 75%, $p=0.001$), employer paid leave (41% vs 52%, $p=0.007$)

Females more likely to have schedule predictability (88% vs. 74%, $p<0.001$), less schedule inconsistency (41% vs. 57% $p<0.001$), and more likely to have PTO (78% vs 66%, $p=0.002$), health benefits (76% vs. 69%, $p=0.04$), a retirement plan (72% vs. 60%, $p=0.009$). Race was not significantly related to workplace supports due to small sample size of many ethnic groups. Most participants spoke primarily English and we could not explore differences by language either.

A greater household income was associated with better workplace benefits, such as PTO (80% vs. 67%, $p<0.001$), health benefits (80% vs. 65%, $p<0.001$), retirement benefits (78% vs. 56%, $p<0.001$) and employer provided paid leave (53% vs. 33%, $p<0.001$).

Greater education played a role in schedule authority and consistency with greater education being associated with more frequent schedule change (50% vs 39%, $p=0.003$) but also have greater schedule authority (77% vs 61%, $p<0.001$).

PART 3: Experiences with California Paid Family Leave (PFL)

Who is aware of California PFL? [FILTERS: Eligible for PFL (non-profit and private sector)]

About 1 in 3 working caregivers who are eligible for California PFL are unaware of it. About 38% of people know someone who has used it and just 16% of eligible working caregivers have applied for PFL. Not all who applied received claims (63%) however.

How does awareness differ across demographics and work environments? [FILTER: Eligible for PFL)

About 64% people in private sector have heard of PFL. Comparably, 72% of people in nonprofits settings are slightly more likely to be aware. PFL awareness is low in the retail industry (52% vs. 68%, $p=0.02$). In general, those working in potentially more “professional” settings like finance, social services have greater knowledge of PFL (not statistically significant). Those working in health professions have significantly greater awareness (73% vs. 64%, $p=0.04$).

People working in places with more employees generally more likely to be aware of PFL, more likely to say it was easy to understand, more likely to understand it well enough to explain it to someone else $p=0.02$ - $p=0.03$. For example, 73% of people in environments with 50+ employees knew about PFL compared to 63% and 53% of participants in work sizes of 11-19, 1-10 people respectively.

People who have higher wage more likely to know about PFL, ($p=0.001$), in a graded manner. For example prevalences of awareness for people who earned hourly wages up to \$19.99, \$29.99, and \$30+ was 54%, 68%, and 72%. About 50% of workers who earned between \$10.51-\$13.99 know about PFL. People with greater education ($p=0.02$) and household income ($p=0.002$) generally more likely to know about PFL, in a dose-responses relationship, for example 35% of those with up to a high school education vs. 68% of those with a bachelor’s degree know about PFL, and 72% of those with a household income of \$60,000+ knew about PFL versus 55% of those in the lowest income

bracket (\$0-\$44,999). Finally, females are more likely to be aware of PFL (72% vs. 43%, $p<0.001$) than males.

How does understanding differ? [FILTERS: Eligible for PFL and Aware of PFL]

Those working in the private sector less likely to feel comfortable explaining PFL to someone else (29% vs. 40%, $p=0.03$), and those working in the health industry felt more comfortable explaining PFL (42% vs. 28%, $p=0.009$). People working in environments with more employees had a greater sense of understanding ($p=0.03$). For example, for those working in settings with 1-10, 11-49, 50+ employees had 20%, 34% and 36% levels of understanding in terms of comfort in explaining PFL to someone else.

Where do participants learn about California PFL from? [FILTERS: Eligible for PFL and Aware of PFL]

Eligible caregivers tend to receive information about PFL through their workplace (46%), followed by family or friends (25%), the internet (13%) and the EDD (13%). About 60% of participants thought that the person explaining PFL did a good job, slightly fewer through it was easier to understand (55%), and less than a third (32%) understand PFL well enough to explain it to someone else.

- People who heard about PFL through work more likely to indicate that the source did a good job (71% vs. 49%, $p<0.001$), it was easy to understand (65% vs. 46%, $p<0.001$), understand well enough to explain it to someone else (42% vs. 22%, $p<0.001$).
- With family/friends as a source, people were less likely to say the source did a good job (51% vs. 63%, $p=0.04$), that it was easy to understand (43% vs. 59%, $p=0.007$), they they understand it well enough to explain it to someone else (20% vs. 36%, $p=0.004$).
- With EDD as a source, people more likely to say they indicate source did a good job (76% vs 57%, $p=0.01$), it was easy to understand (80% vs. 51%, $p<0.001$), and understand well enough to explain it to someone else, (47% vs. 29%, $p=0.01$).
- With medical setting as a source, people thought they understood it well enough to explain to someone else, (54% vs. 30%, $p=0.009$).
- With the web as a source, people less likely to say source did a good job (62% vs. 45%, $p=0.01$), it was easy to understand, (41% vs. 57%, $p=0.02$).

Challenges to applying or considering PFL [FILTERS: Eligible for PFL & aware of PFL]

Among caregivers who are eligible and aware of PFL, 42% did not considered applying. Almost than one in five used PTO (18%), or other workplace accommodation such as working part-time, working from home, or having a flexible schedule (4-10%). About 12% did not consider PFL because they did not want to lose wages. A substantial portion of eligible participants do not think they qualified (13%) and 11% of those *aware and eligible* did not think they qualified.

People also reported issues with accessing PFL as barriers to taking advantage of the program. About 23% of knowledgeable and eligible caregivers experienced challenges relating to PFL such as calling the EDD, little help from the EDD, and issues related to the application like confusion, length of time required, and intermittent leave.

Interestingly, people in the nonprofit sector experienced challenges with PFL (32% vs. 20%, $p=0.02$). Those in the social services sector reported greater burdens (35% vs. 21%, $p=0.02$). Challenges are fewer for private, $p=0.009$ (19% vs. 32%). Younger working caregivers had harder

time with PFL (29% vs. 18%, $p=0.02$). Those who had a challenging time taking time off work also had greater challenges with PFL (33% vs. 21%, $p=0.02$).

What could make it user to use PFL? [FILTERS: Eligible for PFL & aware of PFL)

Almost a quarter of caregivers who are eligible and aware of PFL would like better education about it (24%), followed by guaranteed job protection (19%), and better wage compensation (17%).

Appendix C: Focus group tool with summary of findings

Focus Group Guide

Supporting California's Working Family Caregivers

How many participants are in this focus group? _____

Name of facilitator: _____ Recorder: _____

Date and time of focus group: _____

Location of focus group: _____

Warm up questions (10 minutes)

Question	Notes or Probes
Let's go around and get to know one another	<i>Participants can provide a made-up name, initials, or nickname</i>
Who do you provide care for? For how long?	
What words or terms would you use to describe your role?	<i>For example, people who care for family members don't typically identify as caregivers. What do you prefer to be called?</i>

Experiences as a working caregiver (25 minutes)

Question	Note or probe
What challenges do you face as a working caregiver? In particular, how does being a working caregiver affect your physical, mental, and/or social health?	<i>Discuss physical and mental health, level of stress and energy, financial security, relationships with family and friends. How has caregiving impacted the health of the person who are caring for?</i>
What has it been like to work and care for your family member at the same time?	<i>Discuss workplace scheduling, predictability, flexibility, support from employer/supervisor, benefits, access to family leave laws</i>
How does your employer/supervisor make it easier to provide care?	

What would your employer/supervisor do to make it easier to provide care?	
What (additional/alternative) supports/resources do you use to provide care?	

Experiences with PFL (25 minutes)

Question	Notes or probes
What has been your experience with Paid Family Leave?	<i>NOT USED: Why have you not used PFL? How would you like to learn more about it? What would allow you to use it? USED PFL: What has been your experience using PFL? How would you like to learn more about it or better understand it? What changes can be made?)</i>
How has using PFL impacted you?	<i>Discuss your physical and mental health, level of stress and energy, financial security, relationships with family and friends. How has using it impacted the health of the person who are caring for?</i>

Closing out focus group (5 minutes)

Ask the group if they have anything else that they would like to add: *This concludes our focus group. Is there anything else you would like to share with us?*

Summarize what happens next (from above). Thank the group for their participation: *Thank you very much for your time – we know you are incredibly busy. Please feel free to reach out to us if anything else comes to mind that you would like to share.*

Focus Group Findings

Summary

The Spanish/retail worker focus group focused heavily on the unique and varying caregiving situations of the individual participants. Participants spoke of the impacts of care on their lives, families, the experiences of the person who was ill, often terminally ill. Some elements of culture were apparent through obligations of care, caring for chosen family, gender roles in caring, and support amongst the Latino community, for example, through “collections” or donations. A major theme was the role of financial knowledge or education. There was an interesting discussion about the community valuing saving money, whereas other disagreed that this sometimes isn’t even an option. Participants also emphasized solutions for caregivers, such as a fund at the workplace for employees to draw from, or workshops about managing money

There was very little discussion about workplace supports or needs in terms of scheduling challenges, although some participants very briefly would like flexibility. No one in the group knew about PFL. Participants liked the idea of compensation for care, they suggested the the medical setting would be an important source of sharing that information. There was also interest in having training or license for family caregivers around some of the activities that nurses typically engage but are carried out by caregivers. The focus group concluded with a desire to continue to have these conversations - have more focus groups, increasing awareness of caregiving issues, having material translated.

Themes

- Caregiving role descriptions focused on family obligation and spirituality (i.e. “angels on earth” with deep emotional support)
- Impacts of caregiving (stress, changes to life/routine including work, impacts on additional family members; positive impacts include gratitude and fulfillment)
 - “I took care of my mom for almost 5 years and honestly it affects your family a lot, not only the person caring for them but everyone who interacts with them too.”
 - “I stopped doing a lot of things, I changed my life and my routine. When she was awake I would do the housework, when she was asleep I would sleep. I changed my life completely.”
 - “it is stressful, I felt like I was a part of it [illness] because I spent so much time with him and it was really sad to see the despair in that he didn't want to die he wanted to seek out any opportunity he could to save himself and stay. It is really hard to know that you are terminally ill and to see you are going even faster than the days are long- he wanted to do more but life was leaving him.”
 - “I had to stop working a little more, cut my hours, if I want my child to progress a little more and spend more time with him, so I left work. Not completely but I did drop days, and that also affects you.”
 - “... for me it's something that fills my heart, knowing that he needed every one of us and it was about making sure he didn't feel alone during that time as it was happening. Only he and god knew what pain he was feeling and it pained me a lot to see him lying in that bed.”
 - “I feel like I have maybe had to sacrifice lots of things but I also feel like it has been gratifying to try to help little by little, and for here how it changed- well it changed all of us.”
- Financial support in the workplace and community (“Collections” (i.e. community fundraisers, donations) as part of Latino culture)
 - “At work we also do collections and they help too- we we're not a foundation we are a few neighbors where about 10 of us get together. When someone dies, a young person or someone without the resources we do a food sale- we ask to use someone's house or somewhere else and most of the food is donated from knocking on doors. We do put down a little money out of our pockets but at least for me it's minimal, we do the sale and although it wasn't a lot put into it when we sell the food it always comes out to \$1,700-2,000. There have been sales- one of them we made \$4,500 another one was \$6,000- almost got the \$7,000 and the smallest ones are \$1,000 to \$3,000”

- Managing finances discussion focused on cultural values of saving money)
 - “I feel like sometimes latinos aren't totally knowledgeable about how to save money for an emergency (no, it's not really done) It's sad to say but when someone passes away we go around with a little box like this and that is so sad to see that we're not knowledgeable in that way. (I think that we're...) My point is why do we get to that point if we have the money to buy some name-brand glasses, or some shoes why not put away \$20 and say- you know what? death is going to catch up to all of us- and say this is going to be for an emergency.”
 - “The day will come when I die, I don't want my family to go around with a little box I say here is everything, I want to be cremated- everything we do for others is nice, but it is also sad we aren't knowledgeable.”
 - “it's not about being knowledgeable or not, it's that sometimes our situation is different. Thank god she has her husband, and like she said her family is really united. In my case I don't have that, it's not her doing that she is or I may not be but I am alone- and it's not that out there because there are a lot of women who are alone and sometimes the situation is just really different. I have my four kids and like she said she takes out \$20 here and there but sometimes that doesn't have to do with being knowledgeable of having to go out with your box and ask for money”
 - “I think there are situations like she said that there really isn't space to be saving...the rent and the food, clothing, and they say ‘you can do it, you can do it, you can do it’ but the circumstances sometimes don't allow it”

- Participants had ideas about financial education, and training on caregiving
 - “death is the only thing that is certain but it's hard to understand, to prepare- to learn about or go to workshops, because there are workshops about managing your finances, your money.”
 - “I think those basic questions like ‘what would you do’ ‘what can we do for our workers’ like how our employers can help us (financial education) I think that education and like we said- for them to take like a percentage. Seeing it as something normal, for it to start at the bottom because if they say ‘I am going to teach you how to be ready for death’ a lot of us won't accept that (it is really hard because a lot of us don't talk about that, it's taboo right?) Yes, it's taboo so because of that it would be best for the employer to help us in some way like how our taxes are taken out, they should give us that benefit in our pay.”
 - “I feel everything should be equal not where I have papers so I do get this, ... it should be equal because we all work the same and it's not like... because I have papers we aren't the same.”
 - “...we all started caring for people out of a need not because it's our profession. So it's really important for the people with that background in those cases- the nurses, doctors, social workers... all of those people should let us know those of us who are caring for patients from a need, they should give us the information [about PFL].”
 - “I think it would help us a lot if they paid those of us providing care for other people because it's a job ...because if you don't work you don't get paid, and more for people like me and [name] who are servers- if you don't work that day and you don't get tips then you're screwed.”
 - “I would like for them to certify us like a job because if we're already doing it- there's a saying ‘it doesn't matter what you study without experience’ so we don't have the studies but we have the experience that someone who might be studying it

doesn't, it's not the same to say it than to do it so I think it would be a good idea to not have to go to a workshop because we're already doing it but to get the certification, or maybe a workshop to reinforce what we're already doing but to get the certification to work to care for other people”

Appendix D: Caregiver interview tool with summary of findings

Caregiver Interview Guide

Supporting California's Working Family Caregivers

About this project

California's PFL Program allows [eligible](#) workers to take up to 6 weeks of partially paid leave from work to care for a sick family member. Research shows that caregivers are underutilizing the program, and awareness of the program's caregiving component is low, especially among low-income groups. CWFC is interested in conducting research to understand the barriers of low-income groups in accessing the program for caregiving, as well as their specific needs in providing care. Lessons from the research, conducted by HIP, will inform further research, advocacy and campaign efforts over the next three years so that low-income caregivers are better able to access resources necessary to provide care.

Your participation

Your name was provided by CWFC as someone who would add a valuable perspective to the topic of caregivers' barriers to accessing PFL and their specific needs. We appreciate your openness to providing your expertise and insights on this topic. We believe that information from you will help us better understand the issues described, as well as inform the project overall, including upcoming research with caregivers through surveys and focus groups.

About this interview

This interview will likely take place over the phone at a time convenient for you with a research staff member from HIP. The interview will take about 1 hour and will focus on the questions below. With your permission, we would like to audio record the interview to assure accurate comprehension on our part, as well as to pull quotes that could help us tell the caregiver story powerfully. Overall, your perspective will be combined with other interviewees. We will ask you to review any specific quotes or identifying details before including them in the report.

Interview Questions

1. Who do you provide care for? For how long?
2. What words or terms would you use to describe your role?
3. What challenges do you face as a working caregiver? In particular, how does being a working caregiver affect your physical, mental, and/or social health?
4. What unique challenges do you face, if any, as parent of child with illness/disability?
5. What has it been like to work and care for your family member at the same time?
6. How does your employer/supervisor make it easier to provide care?
7. What would your employer/supervisor do to make it easier to provide care?
8. What (additional/alternative) supports/resources do you use to provide care?

9. What do you know about California's Paid Family Leave (PFL) program?
10. If you have used PFL, what has been your experience with it? How has it impacted you?

Caregiver Interview Findings

We interviewed 6 working caregivers who identified as: API, LGBTQ, age 50+ caregiver, a parent of a chronically ill child, a caregiver of 2+ family members, and caregiver who used PFL. Here is a description of the experiences of each unique caregiver connected to their affiliated identity. These caregivers are not representative of all caregivers with this identify, instead they provide insight into some of the unique experiences with that identification.

- The API caregiver described the stereotypical perception about Asians being required to care for their family members when in fact there is a deep desire to care aside from values and obligations. API caregivers, like other ethnic groups, tend to have an added role in needing to translate information from providers to their loved ones. The caregiver emphasized the importance of enhancing translation services in medical and care-related settings.
- The LGBTQ caregiver described perceptions of availability of having free time (due to not having kids) and expectations around using that time to care more than other family members could. This caregiver also described the lack of emotional support from family for one's personal experiences navigating life and relationships as an LGBTQ individual.
- The age 50+ caregiver did not identify with the typical experiences of older working caregivers who might be sandwiched between generations - a generation of children and parents that both needed care and support. This caregiver does not have children and had support from siblings to provide care to a parent, and therefore did not experience significant challenges as someone who is "sandwiched" might be. This caregiver also had a steady and established career and may not reflect hardships of all older workers.
- The parent of chronically ill child described the very involved nature of the role, including tending to any and every need of the child and anticipating action in response to potential changes in health. The parent also expressed that being in this role would be impossible with having a rigid work schedule and expressed gratitude for workplace flexibility.
- The caregiver of 2+ family members described the extreme challenges with negotiating care between two close family members, as well as the relationship dynamics between the family members, and between the caregiver and each care recipient. An added layer was that of mental health diagnosis of one of the family members and how that created added stress in understanding how to best be helpful.
- The caregiver who used PFL expressed a lot of frustration with PFL. The caregiver was not initially aware of the program and was confused among the multiple laws. The caregiver received support from the work environment to navigate the program. Two of the most frustrating components regarding PFL was being able to speak to someone at EDD over the phone, and navigating intermittent leave using the designated time sheet. The caregiver

provided feedback for improving the program but overall felt pessimistic about using it again, especially for intermittent leave.

Although these individuals had different situations, they shared some similar experiences. With the exception of the parent caring for her chronically ill child, most carers were caring for their chronically ill parent, such as a mother or father. The way these individuals described their roles seemed to fall under one of two categories - duty oriented (describing the tasks they carried out), or obligation-oriented (describing their role through their relationship, i.e. “being a good daughter”).

All individuals experienced challenges with working and caring. Compromised physical and mental health and social life was commonly mentioned. Impacts on work productivity, and feeling guilty about not doing enough to be good at work or at caring was also highlighted. Caregivers often mentioned that work was an escape from a life of caregiving. The challenge were especially difficult when lengthy travel was involved.

For the most part, employers were very empathetic and supportive about accommodating employees who were caring, for example through allowing working from home, or shifting work hours. Caregivers overall had no complaints about their work situations or ideas for improving flexibility to care. It is noteworthy that all of the people we spoke to were professionals (lawyers, researchers, etc.). The parent of a caregiver and one caregiver retired early in order to care. The remaining carers had systems set up - networks of family and friends, an IHSS worker, a nanny, etc. It seemed feasibly impossible for carers to take sole responsibilities of working and caring for their loved one.

Most caregivers did not know about PFL in-depth, except the caregiver who applied for it and is currently using it. When participants knew about it, they felt that it was insufficient for long-term care or risked employer retaliation. Mostly, carers used flexible scheduling or time off to care. The caregiver who applied has strong resentment for the program and highlighted frustration with coordinating paperwork with doctors, calling and being able to speak with someone at the EDD, and taking interim leave.