

# PAID FAMILY AND MEDICAL LEAVE



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## Introduction

Paid family and medical leave empowers workers to take time away from work to address their own serious medical condition, to care for a family member with a serious medical condition, or to spend time with a new baby or a newly adopted child. As highlighted in a report by **The Arc and the Georgetown Center on Poverty and Inequality**, paid family and medical leave can be an important support for nearly all workers at some point over the course of their lives, including workers with disabilities. **But major gaps exist.** Currently, only 1 in 7 U.S. workers has access to paid family leave, fewer than 2 in 5 has access to paid medical leave through an employer-sponsored short-term disability insurance policy, and most lack access to dedicated parental leave.<sup>1</sup>

Some U.S. workers, include several of the people profiled below, are able to use vacation days, sick days, or personal days to take paid leave to meet their personal and family support needs. But all too often, workers can't get any paid time off or don't have enough days to address a serious medical condition. Many workers also fear losing their job or other workplace repercussions. In these situations, workers face a cruel and unnecessary tradeoff: health and family, or work and financial stability.

**The stories below highlight the benefits when workers can use paid leave to meet their health and caregiving needs, and the harm when workers can't get the paid leave that they needed.** All highlight why a comprehensive, national paid family and medical leave program is so important.

<sup>1</sup> "Table 32, Leave Benefits: Access, Civilian Workers, March 2016" and "Table 16, Insurance benefits: Access, Participation, and Take-up Rates, Civilian Workers, March 2016." U.S. Bureau of Labor Statistics, National Compensation Survey, March 2016. Available at <https://www.bls.gov/ncs/ebs/benefits/2016/ownership/civilian/table32a.pdf> and <https://www.bls.gov/ncs/ebs/benefits/2016/ownership/civilian/table16a.pdf>.

Read the full report:

**[thearc.org/file/public-policy-document/Paid-Leave-Report.pdf](https://thearc.org/file/public-policy-document/Paid-Leave-Report.pdf)**

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## Angela's Story:

*We are very fortunate, but not everyone has access to flexible paid time off.*

ANGELA, VIRGINIA RESIDENT

When I received my breast cancer diagnosis, my son with Williams Syndrome was about half-way through his first year in a new school. My husband was supporting us in his government job, and I had taken the role as our son's primary support at home. My son doesn't have significant medical support needs, but he does require significant behavioral, functional, and academic supports. In the weeks following my initial diagnosis of Invasive Ductal Carcinoma (that had spread to my lymph nodes), I worked with my doctors to develop a treatment plan, and it immediately became clear that my role at home would change immensely. Throughout those four months of chemotherapy and my subsequent recovery from surgery, my husband needed to fill the gap my treatment created at home and with our son. Thanks to government workplace policies, my husband was able to routinely work from home and use his remaining vacation and sick leave to be available to provide the everyday supports our son requires. Further, thanks to generous leave donation programs, he was able to do this without worry that he



would run out of vacation time. We are very fortunate, but not everyone has access to flexible paid time off or leave donation programs. A national paid family and medical leave policy is absolutely vital for everyone—workplace circumstances should not force families to choose between the health and safety of a loved one and a pay check.

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## Erika's Story:

*I wasn't unique in wanting to help my family, simply lucky I had the benefits.*

ERIKA, NORTH CAROLINA RESIDENT

When I was in my twenties, my mom lost her four-year battle with melanoma. I took a day of leave here and there in concert with family members to support her after surgeries and intrusive treatments. But when end of life was near, I pieced together my remaining personal and sick leave for her last month of in-home hospice care. This allowed me to help shoulder a significant portion of my family's efforts to manage her medications, order and install medical equipment, organize limited medical and faith community supports, and offer her as much comfort and love as we could. I would have done anything to ease her suffering and offer my dad some relief. I remember family and friends praised me for being a "good daughter" because I took time to care of her, but their praise confounded me. My mom, the woman I loved most in the world, was dying. She needed me, and my family needed me. My family worked tirelessly to find me the supports I needed growing up with a disability. It was my turn. The difference between me and many other daughters who



would have given anything for the same opportunity was paid leave. I wasn't unique in wanting to help my family, simply lucky I had the benefits to make it happen. Families don't need luck and praise, they need the certainty and support of paid leave.



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## Denise's Story:

*I eventually took an unpaid leave...which put a significant strain on our finances.*

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DENISE, MARYLAND RESIDENT

I was working as a contract employee and looking forward to the birth of my daughter. I hadn't been with my employer long enough to get full benefits, but by my due date I would have a month's leave plus a week or so of vacation time that I was planning to use to spend time with my new baby after the birth. I thought I had a plan. That was before my daughter arrived not at full term, but at 12 weeks BEFORE full term. My daughter was born by a traumatic emergency C-section at 28 weeks, weighing less than 2 pounds. She went on to spend nearly 12 difficult weeks in the Neonatal Intensive Care Unit (NICU), with my not knowing whether she would live or die during her first month. Yet, I had to return to work one month to the day that she was born so that I would preserve my remaining leave and vacation days for when she would come home. That meant two-a-day trips to the NICU for the majority of her time there while also working a full-time schedule, despite not being fully physically healed from the C-section, to say nothing of my emotional healing from the trauma of it all. I eventually took an unpaid leave of absence to cover the majority of the time that I was home with her (about 2 months), which put a significant strain on our finances that



we're still—4 years later—digging out of. While I returned to work after my paid and unpaid leave of absence, I left the company within a year. I am convinced that had I received paid leave for six months, which is what is in many developed countries, I would still be with the company. The good news is that my daughter is now 5 years old, and she's thriving. She's now in school, and she has an individualized education plan to help her get the services she needs.

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## Steve's Story:

*This experience led my wife and me to advocate for paid leave.*

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STEVE, NEW JERSEY RESIDENT

Like most new parents, we planned ahead for my wife's maternity leave, assuming everything would go according to plan. When Stephanie was born in 1992, we learned she had a solitary dysplastic kidney, functioning only at 15 percent. Stephanie needed a parent home with her for the first six months. We quickly exhausted my wife's accumulated sick and vacation time. With both of us back at work, we had Stephanie in an in-home daycare with just a few other children, but Stephanie kept getting sick; the doctor said she needed to build up her immune system before she could be around other children. In 1993, the federal Family and Medical Leave Act had just passed, so we could take leave to care for Stephanie without worrying about our jobs—but the time was unpaid. We didn't live an extravagant lifestyle—we had no student loans or credit cards, and we didn't even have cable TV. But this second round of taking leave to support Stephanie put us \$20,000 in debt—we almost lost our home. For the first time, we took out a credit card and put our mortgage on it. It was scary. It took us several years



to regroup, and find some financial stability. This experience led my wife and me to advocate for paid leave in our home state of New Jersey—a program that's thankfully now in place. We have to take the next step and enact a national paid family and medical leave policy—for all the families like mine who find themselves in need, at any point in life.