

# **Security & Stability:**

# Paid Family and Medical Leave and its Importance to People with Disabilities and their Families

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# **Introduction**

Nearly 1 in 5 people in the United States have a disability (40 to 57 million,[[1]](#endnote-1) and potentially more).[[2]](#endnote-2) Physical, mental, and sensory disabilities affect people of all ages, including around 3.7 million children, 26.3 million working-age adults, and 17.4 million seniors.[[3]](#endnote-3) And with the aging of the population, the share of the population with disabilities is expected to rise.[[4]](#endnote-4) With fewer non-working adults in households than in generations past, unpaid caregiving responsibilities increasingly fall on workers.[[5]](#endnote-5),[[6]](#endnote-6) In addition, increased use and recognition of modern family structures have helped illuminate gaps in current work-family policies. The prevalence of disabilities across the lifespan and changing demographic landscape indicate the need for more comprehensive policies that can address the realities of modern work-family balance needs.

Paid family and medical leave (PFML or “paid leave”)[[7]](#endnote-7) empowers workers with the freedom to balance competing personal, financial, and workplace responsibilities. Research has demonstrated that access to paid leave can be transformative for health and socioeconomic well-being.[[8]](#endnote-8) At the same time, economic stability for individuals with disabilities, including through employment, has for decades been a core goal of the disability rights movement, promoting the full participation and inclusion of people with disabilities in all aspects of community life.[[9]](#endnote-9) Like all workers, workers with disabilities may need to access paid leave to welcome a new child, to provide care for a family member with a serious medical condition, or if they experience their own serious medical condition. Despite policymakers’ apparent interest in both paid leave and in increasing employment and economic security among households with disabilities,[[10]](#endnote-10), [[11]](#endnote-11) the two issues are rarely discussed together.

Job-protected paid leave has wide-ranging benefits for workers and their families, employers,[[12]](#endnote-12) and society as a whole.[[13]](#endnote-13) Well-designed paid leave promotes employment and income security:[[14]](#endnote-14) it is associated with higher overall labor force attachment,[[15]](#endnote-15), [[16]](#endnote-16) improved employee retention, and talent attraction, all with little to no harm to employers.[[17]](#endnote-17), [[18]](#endnote-18) Recognizing these and other benefits, majorities of voters[[19]](#endnote-19), [[20]](#endnote-20) and many employers[[21]](#endnote-21) support paid leave. States and localities throughout the country are also increasingly exploring and adopting paid leave policies.[[22]](#endnote-22)

The United States is far from achieving a system of universal and equitable paid leave with adequacy that matches the reality of family and medical needs today. While progress has been made at the state and local levels, and some employers offer certain workers some paid leave, the United States stands virtually alone among wealthy countries in not guaranteeing PFML.[[23]](#endnote-23) Just 68 percent of all civilian workers have access to any paid sick leave to address one’s own health condition; only 14 percent have access to paid family leave that they can use to address a serious health condition of a family member.[[24]](#endnote-24) Most workers also lack access to dedicated parental (maternity or paternity) leave to care for a newborn baby or newly adopted child.[[25]](#endnote-25), [[26]](#endnote-26)

Lack of paid leave can force a cruel and unnecessary tradeoff: health and family, or work and financial stability. Workers often cannot afford to jeopardize their job security by taking time off or forgoing lost wages each time they or a family member needs support.[[27]](#endnote-27) For workers with disabilities or workers who are unpaid caregivers of family members with disabilities, this tradeoff can be especially daunting. As described in this report, people with disabilities and their families on average are more likely to have lower incomes and savings. They are also more likely to face barriers to employment that can render the financial impact of unpaid time off particularly devastating.

The purpose of this report is to explore the importance of paid medical, family, and parental leave for workers with disabilities and unpaid family caregivers (who may or may not themselves have a disability) of children, parents, or other family members (working or not) with disabilities. In other words, the report focuses on paid leave for both people with disabilities who receive care and people with or without disabilities who provide supports and services to them. The report begins with a brief overview of statistical data on disability and work in the United States. It then explores the benefits of paid leave for people with disabilities and their families before providing an overview of current access to and utilization of paid leave. Finally, it outlines principles to maximize the impact and reach of paid leave for people with disabilities and their families.[[28]](#endnote-28)

# **Disability and Work in the United States**

To develop an understanding of the importance of paid leave for people with disabilities and their families, this section highlights key demographic data describing disability in the United States.[[29]](#endnote-29), [[30]](#endnote-30) We estimate that there are 26.3 million working-age adults with disabilities, along with 36 million working age adults with family members with disabilities.[[31]](#endnote-31) For the purposes of this report, we estimate that approximately 47.1 million Americans have disabilities.[[32]](#endnote-32) These individuals and their households are diverse, but having a disability is more common among some groups, as noted below.

[Start of Text Box 1]

##### ECONOMIC INSECURITY AND DISABILITY ARE INTERTWINED

The causes and effects of disability are intrinsically tied to issues of economic insecurity and instability—which disability can cause or result from. As the Center for American Progress has noted, disability can cause insecurity because “disability or illness can lead to job loss and reduced earnings, barriers to education and skills development, significant additional expenses, and many other challenges that can lead to economic hardship.”[[33]](#endnote-33) Disability can also be a consequence of income insecurity and volatility,[[34]](#endnote-34) which are associated with numerous factors that can exacerbate disabilities and illnesses, including limited access to health care and preventive services,[[35]](#endnote-35) greater risk of hunger and inadequate nutrition,[[36]](#endnote-36) and increased exposure to environmental hazards[[37]](#endnote-37) and workplace hazards.[[38]](#endnote-38), [[39]](#endnote-39) Disability’s connection with insecurity can be exacerbated by inadequate and non- inclusive work policies and practices.[[40]](#endnote-40)

[End of Text Box 1]

Disability is Prevalent Throughout the Life Course

Disability can occur at any age, but older age is associated with higher disability rates. In 2015, while only 13 percent of people age 18 to 64 reported experiencing disability, more than half of those age 75 and above did so.[[41]](#endnote-41) A worker entering the workforce today faces a 1 in 3 chance of becoming disabled for 3 months or more during their working career.[[42]](#endnote-42) The odds of being disabled for a healthy 35- to 45-year-old male during his working career is about 1 in 6.[[43]](#endnote-43)

Workers of Color with Disabilities Face Disproportionate Barriers to Employment and Economic Security

The data also show a significant difference among racial groups of both the incidence of disability and the labor force outcomes for people with disabilities. In 2015, African Americans (19 percent) and American Indians and Alaska Natives (22 percent) saw a greater incidence of disability than Whites (17 percent) and Asian American and Pacific Islanders (8 percent).[[44]](#endnote-44) People of color with disabilities also experienced much higher rates of joblessness than White people with disabilities. Among individuals with a disability in 2015, the unemployment rate for African Americans (25 percent), far surpasses jobless rates for Whites (15 percent).[[45]](#endnote-45) Research also suggests that among women with disabilities who received vocational rehabilitation services or are receiving Social Security Disability Insurance or Supplemental Security Income, African American women are less likely to be employed than White women.[[46]](#endnote-46)

Most Adults with Disabilities are Striving to Work, but Often Face Barriers to Employment

Even after controlling for gender, race, ethnicity, level of educational attainment,[[47]](#endnote-47) or age,[[48]](#endnote-48) having a disability is linked with increased rates of unemployment and underemployment, and a decreased likelihood of being in the workforce. In 2015, 75 percent of people aged 18 and above without disabilities in the U.S. were employed, and their unemployment rate was 7 percent.[[49]](#endnote-49) In stark contrast, only 34 percent of people with a disability were employed, and their unemployment rate (16 percent) was more than twice of that among their counterparts without a disability.[[50]](#endnote-50)

Despite these gaps, adults with disabilities are striving to work—40 percent are currently working or are looking for work—but often face great barriers both in the workplace and job search.[[51]](#endnote-51) In the workplace, 17 percent of current workers with disabilities report getting less pay than others in a similar job, 16 percent report negative attitudes on the part of their supervisor, and another 16 percent report negative attitudes on the part of their coworkers.[[52]](#endnote-52) Fully 1 in 3 employment discrimination charges filed with the U.S. Equal Employment Opportunity Commission allege discrimination on the basis of disability.[[53]](#endnote-53) Job seekers with disabilities report a variety of barriers in the job search process, including employers assuming they cannot do the job (36 percent) and a lack of transportation to travel to interviews or a job (26 percent).[[54]](#endnote-54)

Workers with Disabilities are More Likely to be in Part-Time, Lower-Wage Positions

Among the people with disabilities who are employed, work is more likely to be part-time and in positions with lower wages.[[55]](#endnote-55) In 2015, working-age people with disabilities’ median personal income was approximately $12,100, which was half the national median income among all working-age people.[[56]](#endnote-56) About 40 percent of workers with a disability were employed part-time in 2015, as opposed to roughly 30 percent of those with no disability.[[57]](#endnote-57) One in every four individuals with a disability lives in poverty.[[58]](#endnote-58) In fact, individuals with a disability are more likely to experience long-term poverty: 65 percent of those living in long-term poverty (over a 48-month period) are individuals with a disability.[[59]](#endnote-59)

Workers with Family Members with Disabilities are More Likely to Experience Undesirable Labor Force Status

As noted above, disability and economic insecurity are often intertwined. The approximately 36 million working age people who live with at least one other household member with a disability experience lower labor force participation rates (68 percent), higher unemployment rates (13 percent), and are more likely to be working part-time (35 percent) than their counterparts who have no additional household members with disabilities. They are also more likely to live in poverty (18 percent) or near poverty (40 percent) than the national averages.[[60]](#endnote-60)

Maintaining the balance of work and care duties is difficult for workers in general, but it is particularly challenging for workers who also provide unpaid support and care to family members. A recent survey by the National Alliance for Caregiving (NAC) and AARP found that 6 in 10 unpaid caregivers reported experiencing at least one impact on work or change to their employment situation as a result of caregiving, such as cutting back on their working hours, taking a leave of absence, or receiving a warning about performance or attendance, among other such impacts.[[61]](#endnote-61) One survey found that more than 70 percent of family caregivers for people with intellectual disability and developmental disabilities reported that caregiving interfered with their work and 20 percent reported that someone in the family quit their job in order to provide care.[[62]](#endnote-62) The same survey also found that parents whose child had intellectual disability/developmental disability reported due to their child’s health, they had not taken a job (36 percent), changed work hours (29 percent), worked fewer hours (26 percent), quit working (17 percent), or turned down a better job (17 percent).[[63]](#endnote-63)

Families with Members with Disabilities Experience Worse Economic Outcomes

Across multiple measures, families that include one or more person(s) with a disability (child, adult, or senior) have less secure household finances. More than a quarter (29 percent) of U.S. households have at least one member with a disability.[[64]](#endnote-64) Households with one or more members with a disability have an average household income of about $51,600, compared to about $70,500 for households where no household members have a disability.[[65]](#endnote-65) Over half of households with at least one working-age adult with a disability live in or near poverty (200 percent of the Official Poverty Measure or below).[[66]](#endnote-66) Six in every 10 households caring for at least one minor child with a disability live in or near poverty.[[67]](#endnote-67)

Households that include one or more members with a disability have an average net worth of $62,375, or roughly two-thirds of the net worth of those without one ($90,350).[[68]](#endnote-68) Households with one or more members with a disability also have assets in a financial institution ($2,250) worth half of those held by households with no member with a disability ($5,000).[[69]](#endnote-69) This disparity is also present in long-term savings: households with one or more household members with a disability have $10,000 less in retirement savings than those without one.[[70]](#endnote-70)

# **The Importance of Paid Leave for People with Disabilities and Their Families**

Paid leave is a core part of a health and economic security system that supports work, independence, financial stability, and opportunity for people with disabilities and their families, especially in low- to middle-income working households. Individuals with disabilities and their families commonly experience ongoing tensions between demands on household finances, health and well-being, and work. To be sure, paid sick days, fair scheduling, workplace accommodations, civil rights enforcement, and other strategies are needed to achieve these goals. However, PFML is an essential but underutilized policy tool that can support employment and help mitigate some of the demands—both long- and short-term— that workers with disabilities and their families may encounter. A recent report by The Leadership Conference Education Fund interviewed low-wage workers and found that many fear that “staying home when they or a loved one are sick or in need will mean not only the loss of a day’s pay but also the possible loss of their job.”[[71]](#endnote-71) When workers have access to paid family and medical leave, their options for taking care of themselves and their families expand. Below, some of the key benefits of PFML for people with disabilities and their families are profiled.

[Start of Text Box 2]

##### WHAT IS PAID LEAVE?

Paid family and medical leave (PFML) refers to the ability of workers to receive partial or full compensation for short- to long-term periods while providing or receiving care or rest for one’s own or a family member’s serious and/or chronic health condition, or caring for a newborn or newly adopted child. Generally PFML is categorized into three kinds: personal, parental, or family. Recognizing that what is meant by “paid family” versus “parental” leave can overlap, this brief focuses less on those distinctions and instead characterizes leave in terms of its relationship to the worker—e.g., whether the leave is for one’s own or a family member’s needs.[[72]](#endnote-72)

Paid family and medical leave typically—but not always—includes job protection, and can also include a guarantee that employer-sponsored health coverage will continue during leave and that seniority will be maintained upon return to work. Paid leave can be financed and provided by employers, employees, or some combination of the two. It generally can be used at least somewhat intermittently—for hours or days—rather than all at once or solely in blocks of weeks or months.

Paid leave is generally distinct from but related to a number of other policies that provide pay for time away from work for a compelling reason. One example is paid sick days, which are financed and provided by employers—sometimes due to a government mandate—and are measured in days and often require limited documentation of medical conditions. Paid leave is typically measured in weeks or months, specifies qualifying events, and often requires more extensive medical or other documentation. Paid time off (PTO) provides employees time off for a variety of reasons (i.e. vacation, illness, or personal), but typically does not add up to several weeks or months. PTO is may be combined with paid or unpaid leave for those who have access to these options and require longer periods away from work. Some governments and employers provide short-term or long-term disability insurance, which can be similar or identical to paid medical leave, but do not offer parental leave for births (mothers giving birth are typically covered, but new parents not giving birth are not). In some cases, long-term disability insurance may offer lengthier periods of pay when one is unable to work than paid leave. Finally, temporary caregiver insurance may offer parental leave and leave for caring for a family member who is ill.

[End of Text Box 2]

Paid Leave Boosts Economic Security and Opportunity for People with Disabilities and their Families

Because households that include individuals with disabilities often have low to moderate incomes, any time off taken by a working adult could result in severe economic consequences— and for many, the impact of job loss could be financially devastating. When workers have access to job-protected paid leave, they and their families can avoid some of the pitfalls often associated with taking time off work, including lost income and potential depressed wages in the future.[[73]](#endnote-73) PFML that replaces a sufficient percentage of wages may also enable workers to take time off rather than being forced to switch to part-time work or to a lower-paying job. Part-time work on average comes with less pay, fewer employer-provided benefits, and often less opportunity for career advancement.[[74]](#endnote-74)

Given the labor force barriers and outcomes described above, it is not surprising that people with disabilities in the U.S. and their families often experience significantly greater economic and material hardship.[[75]](#endnote-75),[[76]](#endnote-76) One study estimates that a decade after the onset of a chronic and severe disability, a person on average experiences a 76 percent decline in earnings, a 28 percent decline in after-tax income, a 25 percent decline in food and housing consumption, and a 18 percent decline in food consumption.[[77]](#endnote-77)

Due to lower-than-average income, savings, and wealth, people with disabilities and their families also often face greater financial insecurity. Only 1 in 10 people with disabilities are confident that they could come up with $2,000 for an unexpected need (compared to 1 in 3 people with no disability) and 4 in 5 lack any sort of rainy day fund (compared to just over half of people with no disability).[[78]](#endnote-78) People with disabilities and their families also often pay higher than average out-of- pocket medical costs and may face added disability-related costs, such as for accessible transportation, adaptive equipment, home modifications, or medically-prescribed diets.[[79]](#endnote-79) Compared to people without disabilities, adults with disabilities are twice as likely to say that it is “very difficult” to cover their monthly expenses (31 percent versus 15 percent) and half as likely to say that it is “not at all difficult” (20 percent versus 41 percent).[[80]](#endnote-80) Twenty-two percent of families raising a child with special health care needs report that the child’s health conditions have led to family financial problems.[[81]](#endnote-81)

The combination of lower incomes and higher costs can threaten basic living standards. Families with a child with a disability are more likely to report that it has been very hard to get by on the family’s income and cover “the basics like food or housing.”[[82]](#endnote-82) Thirteen percent of families whose children have “more complex health care needs” report that this happens “very often,” compared to 6 percent of families that do not include a minor child with special health care needs.[[83]](#endnote-83)

As a result, PFML can play an important role in reducing poverty and mitigating the potential for discrimination and exclusion from the workforce.[[84]](#endnote-84),[[85]](#endnote-85)As noted earlier, paid leave can reduce job separations and involuntary time out of the workforce. It allows families to plan, adjust their spending, and avoid premature depletion of savings.[[86]](#endnote-86) It can also positively affect wages. Though this research is not focused on people with disabilities per se, Rutgers researchers found that women with children who took paid family leave for 30 or more days following a child’s birth were 54 percent more likely to report wage increases in the year following than women who took no leave.[[87]](#endnote-87)

Paid Leave Helps Workers with Disabilities Care for Themselves

Workers with disabilities take leave for the same reasons as all other workers. In the United States, addressing one’s own illness is the most common reason that workers take unpaid leave, making up 55 percent of all leave taken; other reasons include a new child (20 percent) and a family member’s health condition (18 percent).[[88]](#endnote-88)

As described above, workers with disabilities are more likely to be employed in low-wage, part-time jobs. On average, such jobs provide fewer supports than higher-wage, full-time jobs if a worker experiences a serious medical condition or has family caregiving responsibilities. For example, access to leave of any type, whether paid or unpaid, is less common in low-wage and part-time jobs.[[89]](#endnote-89) In addition, only 28 percent of workers with disabilities report having “flexible schedules,” or jobs that allow flexible start and end times, working at home, and/or taking more breaks.[[90]](#endnote-90) Flexible schedules, along with other forms of workplace flexibility, can be an important strategy to help people with disabilities to obtain and maintain employment.[[91]](#endnote-91)

Paid leave increases opportunities for workers, including workers with disabilities, to take time off if they experience a serious medical condition without seeing a sharp drop in income or putting their job or employer-based health insurance at risk. This can include leave for both one- time and ongoing health needs. In a 2012 survey, 46 percent of workers who took leave for their own illness did so for a one-time illness, while 38 percent took leave to address ongoing health issues, or for injuries or illnesses that required routine medical care.[[92]](#endnote-92) Unsurprisingly, income stability, employment, and ongoing access to health insurance all have a well-documented association with positive health outcomes.[[93]](#endnote-93),[[94]](#endnote-94),[[95]](#endnote-95) In addition, paid leave can increase access to preventive care, such as going to doctor’s appointments, and lead to better overall health and well-being.[[96]](#endnote-96)

Paid Leave Helps Workers Care for Family Members with Disabilities

Caregiving needs in the U.S. are both prevalent and profound: approximately 2 in 5 adults report caring for an adult or child with significant health issues.[[97]](#endnote-97) This caregiving is most often unpaid and can impact work.[[98]](#endnote-98) A recent survey by the National Alliance for Caregiving (NAC) and AARP found that unpaid caregivers for adults spent over 24 hours a week providing care, on average, with 23 percent spending more than 40 hours a week.[[99]](#endnote-99) In the same study, 60 percent of caregivers for adults reported working in the last 12 months, with 56 percent of those working full time. Roughly 1 in 4 workers report taking leave to provide care for a “seriously ill” family member, and an additional quarter anticipate having to do so in the future.[[100]](#endnote-100), [[101]](#endnote-101)

The lack of a nationwide caregiving infrastructure—for children, adults, and seniors— fosters these high levels of unpaid caregiving and can lead to difficult trade-offs for people attempting to both work and ensure proper support for themselves and/or family members with disabilities.[[102]](#endnote-102) Affordable and quality professional direct support is largely out of reach in the private market for all but the wealthiest families.[[103]](#endnote-103) For some children, adults, and seniors with disabilities, Medicaid home and community-based services (HCBS) help bridge the gap. Medicaid HCBS programs provide access to personal care services and related long-term supports and services for nearly 3 million people across the U.S.[[104]](#endnote-104) However, significant unmet needs remain. For example, all states restrict eligibility, cap enrollment, and/or ration the kinds and amounts of services people can access; over 640,000 people were on waiting lists for HCBS services in 2015.[[105]](#endnote-105)

Faced with these gaps, workers and families often resort to work-arounds to access and/or provide supports for themselves or for immediate family members such as spouses, children, and parents.[[106]](#endnote-106) In addition to help with activities such as bathing, dressing, eating, toileting, transportation, grocery shopping, and housework, many spend significant time navigating service systems and coping with emergencies. For example, parents of children with significant disabilities often must balance work with taking their child to medical and speech, language, or physical therapy appointments; attending school meetings; meeting their child’s daily needs; emergency room visits; and hospitalizations.[[107]](#endnote-107)

To meet these often-significant needs, in the NAC/AARP survey, 24 percent of caregivers of adults age 18 or older reported that they reduced their work hours, took a less demanding job, gave up work entirely, or retired early. Similarly, in a 2009/2010 survey, 25 percent of children with special health care needs had a family member who cut back hours worked or stopped working entirely.[[108]](#endnote-108)

PFML can help workers navigate their family’s needs and help more family members maintain work hours, stay in the workforce, keep careers on track, and address their own health needs. One study found that the odds of a worker losing income increase by 48 percent if the worker lives with a child with special health care needs and by 29 percent if the workers is caring for an adult with health issues—but that having access to dedicated paid family leave reduces the odds of losing income by 30 percent. By stabilizing income and access to health insurance, paid leave helps people with disabilities and their families pay for housing, food, and other basics, access medical care and long-term services and supports, and maintain a life in the community. Other considerations include the often-increased need for PFML after the birth of an infant with special health care needs, both to care for the newborn and for the birth mother to recover. The impact on parents’ employment, time, and finances of caring for children[[109]](#endnote-109) or elderly family members with disabilities has also been well-documented.[[110]](#endnote-110)

Paid leave is particularly important for mitigating the compounded challenges often experienced by unpaid caregivers. First, many family caregivers are women, and women are disproportionately low-income and overrepresented in jobs which are least likely to have access to any kind of leave.[[111]](#endnote-111) Second, there is an increased likelihood that the person for whom they are providing support lives in poverty.[[112]](#endnote-112) Having PFML can help offset some of the expenses associated with providing care and/or taking time off work to do so. Third, caregivers may themselves experience disability, illness, or injury. For example, caregivers providing more hours of care or supporting individuals with more complex health needs are also less likely to report excellent or very good health,[[113]](#endnote-113), [[114]](#endnote-114) and more likely to indicate that caregiving has made their health worse.[[115]](#endnote-115) Access to PFML can help workers balance their personal care needs while working and providing support to a family member. Paid family leave has been shown to boost mental health, and paid sick leave to boost mental and physical health, for workers living with a child or caring for an adult with a chronic illness, medical condition, disability, or other health problem.[[116]](#endnote-116)

Paid Leave Improves Family Well-Being

In addition to providing vital workplace support for families with disability-related needs, paid leave can also have a profound impact at home. By empowering families with the flexibility and resources to make decisions based on what is best for the individual and family, research suggests that paid leave may even help mitigate the impacts of gender and race on family-work expectations and arrangements.[[117]](#endnote-117) Despite an increase in household female work participation rates,[[118]](#endnote-118) women are still more likely to be primary the child caregivers. Sixty-six percent of women in dual-earner couples report taking greater responsibility for routine child care than their male partners.[[119]](#endnote-119) Seventy percent of women also report taking time off from work because of children’s needs, in comparison to only 30 percent of men.[[120]](#endnote-120) Providing universal paid leave may foster a more egalitarian family environment in which adult male household members can take on more child care and household responsibilities, due to both an increase in access to job-protected time off and societal shifts due to changing norms and expectations in the workplace. Women of color, who disproportionally lack access to paid leave, may especially benefit from the increased access to paid leave.[[121]](#endnote-121) Paid leave can also have a positive impact on family well-being. One study of parents with PFML found the majority (57 percent) experienced positive effects from having leave on both their own emotional health as well as the physical and emotional health of their child (81 percent and 85 percent).[[122]](#endnote-122)

**The State of Paid Leave for People with Disabilities in the United States**

A substantial proportion of American workers lack access to one or more types of paid leave through their employers, and those who need it the most are the least likely to have it.[[123]](#endnote-123) This is particularly true for workers with disabilities or family members of people with disabilities, who are disproportionately less likely to have access to paid family and medical leave and are more likely to face barriers due to confounding factors related to income, gender, race/ethnicity, and age, among others.[[124]](#endnote-124) The following section outlines existing and proposed federal and state/local family and medical leave policies in the U.S. It also highlights opportunities to strengthen existing and proposed policies to better meet the needs of people with disabilities and their families.

Key Policies

The U.S. has a patchwork of state and local laws, along with federal disability protections and unpaid family and medical leave.

FEDERAL LAW

More than half of workers in the U.S. have access to job-protected, unpaidfamily and medical leave through the 1993 Family and Medical Leave Act (FMLA).[[125]](#endnote-125) The FMLA requires employers[[126]](#endnote-126) to provide eligible workers with job-protected, unpaid leave for up to 12 work weeks within a 12-month period.[[127]](#endnote-127), [[128]](#endnote-128) FMLA covers “a limited set of family caregiving needs,”[[129]](#endnote-129) including: the birth or placement for adoption or foster care of a child; caring for a spouse, child, or parent with a serious health condition; and serious health conditions that render an employee “unable to perform the essential functions of his or her job.”[[130]](#endnote-130) More recently added provisions also provide leave for caregiving associated with military service and deployment.[[131]](#endnote-131) For workers with disabilities, the Americans with Disabilities Act (ADA) offers additional legal support for job-protected leave.[[132]](#endnote-132), [[133]](#endnote-133) However, there is no national legal requirement for employers to provide any paid leave.[[134]](#endnote-134)

Workers are eligible for FMLA leave if they meet the following conditions: 1) have worked for their employer for at least 12 months;[[135]](#endnote-135) 2) have worked at least 1,250 hours within the past 12 months for their employer; and 3) are employed at a worksite with at least 50 employees in a 75-mile radius.

In all, an estimated 60 percent of workers are eligible under these requirements.[[136]](#endnote-136) Employees of small businesses; new workers who have been at their employers for less than 12 months; and employees who are seasonal, part-year, or in some cases, part-time are excluded.[[137]](#endnote-137) Certain workers, including workers of color, workers with disabilities, and women workers are disproportionately ineligible for FMLA.[[138]](#endnote-138) Low-wage workers are also less likely to be eligible for FMLA leave—let alone paid leave—than high-wage workers. This can be “for a variety of reasons, including lower educational attainment and overrepresentation in jobs with higher turnover, seasonality, and less income security.”[[139]](#endnote-139)

[Start of Text Box 3]

##### INTERNATIONAL COMPARISONS

Family and medical leave protections in the U.S. fall drastically short of what other countries provide to their workers.[[140]](#endnote-140), [[141]](#endnote-141) A comparison of parental leave policies shows a particularly stark difference. Of all countries in the Organisation for Economic Co-operation and Development (OECD), the U.S. only provides protected unpaid leave of 12 weeks.[[142]](#endnote-142) In a recent United Nations study, the U.S. is one of just two countries out of the 170 countries with no law providing mothers with paid family leave after the birth of a child.[[143]](#endnote-143) Estonia provides 87 weeks of paid parental leave, and our neighbors Canada and Mexico provide 27.4 weeks and 13 weeks, respectively.[[144]](#endnote-144)

[End of Text Box 3]

STATE AND LOCAL LAWS

In the absence of a national PFML program, several states and localities have stepped up to fill the gaps. In some cases, states allow eligible workers to combine unpaid leave with state-provided temporary disability insurance benefits to create something similar to paid leave.[[145]](#endnote-145), [[146]](#endnote-146) California,[[147]](#endnote-147) New Jersey, and Rhode Island were the first to implement their policies,[[148]](#endnote-148) and many others are following suit. New York, the District of Columbia, and most recently Washington[[149]](#endnote-149) will begin offering paid family and medical leave in 2018 (NY) and in 2020 (D.C. and WA). While states like California, New Jersey, Rhode Island and New York were able to build paid family leave programs on top of pre-existing Temporary Disability Insurance (TDI), the District of Columbia and Washington have had to establish new funding mechanisms.[[150]](#endnote-150) Many more localities, including Philadelphia, Pittsburgh, Minneapolis, Chicago, and Seattle have enacted different variations of paid sick days laws in recent years,[[151]](#endnote-151) allowing employees to accrue paid sick days for a certain amount of hours worked.[[152]](#endnote-152)

People with Disabilities and their Family Caregivers Are Ill-Served by Current Leave Policies

Paid family and medical leave in the U.S. can foster a functioning, healthy economy and offer an important work support for everyone. In the absence of a comprehensive federal program, many Americans are left out by the existing patchwork of leave systems, and across the workforce access is both unequal and inadequate.[[153]](#endnote-153) Outside the states leading the way with their own programs, paid leave policy remains largely at the discretion of employers.

Depending on the location, industry sector, and individual employers, access to paid leave can be particularly limited for marginalized communities, including individuals with disabilities and people who are low-income;[[154]](#endnote-154) women; young people;[[155]](#endnote-155) lesbian, gay, bisexual, transgender, and queer (LGBTQ); and/or people of color. Examining how people use and do not use paid leave can reveal gaps in the current system—particularly when disability is a factor.

ACCESS TO PAID LEAVE IS LIMITED, ESPECIALLY FOR FAMILIES THAT INCLUDE PEOPLE WITH DISABILITIES

Across the nation, outside of states that have implemented their own paid leave programs, workers have drastically different access to paid leave.[[156]](#endnote-156) Within the overall workforce, just 1 in 7 workers has employer-provided paid *family* leave.[[157]](#endnote-157) Slightly more than 2 in 3 workers have employer-provided sick days, and less than 2 in 5 workers have employer-provided paid *medical* leave through short-term disability benefits.[[158]](#endnote-158), [[159]](#endnote-159), [[160]](#endnote-160) Such “gaps in access to leave and barriers to use it reflect and can amplify underlying workplace inequality.”[[161]](#endnote-161)

People who work full-time, at large companies,[[162]](#endnote-162) and/or “in professional and technical occupations and industries [or] high-paying occupations”[[163]](#endnote-163) are the most likely to have paid leave through their employer.[[164]](#endnote-164) Any worker who falls outside one of these categories or who has additional barriers to employment[[165]](#endnote-165) is significantly less likely to have access to paid leave, including for family or medical care. For example, over two-thirds of all part-time workers in the private sector lack access to even one paid sick day.[[166]](#endnote-166) Inequities are reinforced across the pay scale—a staggering 53 percent “of lower-income workers did not receive pay during their most recent FMLA leave.”[[167]](#endnote-167)

As described in earlier sections, people with disabilities are more likely to work in part-time and low-wage jobs, and as a result are less likely to have access to paid leave.[[168]](#endnote-168), [[169]](#endnote-169), [[170]](#endnote-170) These gaps often persist in states that have established their own PFML programs, because current FMLA and state regulations exclude many workers in part-time and low-wage jobs.[[171]](#endnote-171)

Examining paid leave at the intersections of disability, race/ethnicity, sexual orientation, and gender, among others, reveals additional stark discrepancies. Despite having “better educational credentials than ever,” women—including women with disabilities—are still overrepresented in low-wage work and continue to shoulder a disproportionate amount of household and caregiving responsibilities.[[172]](#endnote-172) For women of color, the likelihood of having access to any kind of paid leave is quite low, as they are overrepresented in the types of jobs (lower-wage, part-time) that typically do not provide such leave.[[173]](#endnote-173), [[174]](#endnote-174) In addition, roughly half of Hispanic/Latina women workers lack access to any paid sick leave.[[175]](#endnote-175)

Many workers and families find FMLA protections to be too narrow and not encompassing of the relationships and structures that are important to different families.[[176]](#endnote-176) For example, a vast majority of households (over 80 percent) do not fit the “traditional” nuclear family model (a married couple and their minor children). As of 2014, 85 million people—disproportionately people of color—lived in extended families.[[177]](#endnote-177) And yet, under the FMLA, family is defined as “a child who is under 18 years of age or has a disability, a spouse, or a parent.”[[178]](#endnote-178) Due to efforts by disability advocates, the Department of Labor (DOL) has clarified that siblings, grandparents, and other relatives can qualify in some circumstances for FMLA leave when acting “in loco parentis” (described in DOL subregulatory guidance as “to take on the role of a parent”).[[179]](#endnote-179),[[180]](#endnote-180) While a significant step, this still categorically excludes anyone who relies on extended or chosen family members, including many LGBTQ individuals.[[181]](#endnote-181) A forthcoming brief by the Center for American Progress estimates that nearly one-third of people in the U.S. report having taken time off from work to care for a chosen family member with a health issue, with LGBTQ people and individuals with disabilities being especially likely to need to take leave to support chosen family.[[182]](#endnote-182) Similarly, the recent increased focus on natural supports and circles of supports for people with disabilities has resulted in a growing number of non-related individuals who would benefit from inclusion in paid leave, such as shared living roommates.

FMLA protections can also fall short of covering many of a family’s needs, whether for a worker’s own medical needs or for caregiving. For example, DOL has clarified that workers can use unpaid FMLA leave in certain circumstances when acting “in loco parentis” for a sibling, but gaps remain.[[183]](#endnote-183) Similarly, the FMLA does not address leave to attend school meetings for children with disabilities under the Individuals with Disabilities Education Act or Section 504 of the Rehabilitation Act.[[184]](#endnote-184), [[185]](#endnote-185)

EVEN WHEN AVAILABLE, PAID LEAVE IS OFTEN OUT OF REACH

Of those with job-protected coverage under the FMLA who did not take time off after a qualifying event, 8 in 10 reported they would have taken leave if it were paid.[[186]](#endnote-186) But even when workers do have access to PFML—through their employer or state family leave insurance—many do not use it.[[187]](#endnote-187), [[188]](#endnote-188) Take-up may be influenced by a number of factors including leave duration and frequency, wage replacement, job protections, and awareness.

As noted earlier, workers with disabilities and their families on average have lower incomes and savings, as well as increased out of pocket medical and disability-related costs. If paid leave benefits do not replace a sufficient percentage of wages, workers who have disabilities or who are caring for a family member with a disability may not be able to afford to take leave.[[189]](#endnote-189) In addition, faced with ongoing negative attitudes and discrimination in the workplace (as discussed above), workers with disabilities may have significant privacy concerns or may fear retaliation if they take leave. If paid leave benefits do not come with assurances such as continued health insurance, job restoration and protection against retaliation, fear of negative repercussions may pose a significant deterrent for workers with disabilities to taking leave.

For example, recent studies of workers in California and New Jersey[[190]](#endnote-190) (which have paid leave programs) found that limited public awareness, insufficient replacement rates, and gaps in leave coverage, among other factors, may limit take-up rates. In those states, “low-wage workers, immigrants, and Latinos—groups that overlap significantly—were least likely to be aware of the program.”[[191]](#endnote-191) In addition, depending on state of residence and whether they are covered by FMLA, workers may or may not have job-protectedpaid leave. The studies of workers in California and New Jersey found that some did not take paid leave, even when they had the option, because they were afraid of losing their jobs.[[192]](#endnote-192) Pairing PFML with adequate job security measures may be particularly important for people with disabilities, as they are more likely to experience discrimination in the workforce, as well as workers providing support to family members with disabilities, who may fear adverse consequences from taking time off from work.

Such findings suggest a well-functioning PFML policy requires public outreach and buy-in on the part of the employer; importantly, public outreach and education must be fully accessible to people with disabilities. In addition, a well-functioning PFML policy needs to include features that address workers’ concerns for economic and job security. Another important takeaway is that absent a national, comprehensive PFML policy, efforts by states and localities—while an important step forward—may have modest impact for workers with disabilities and their families.

# **Conclusion and Policy Recommendations**

Workers with disabilities and their family members need a range of supports to ensure fair outcomes at work while addressing their family and serious health needs. These supports include programs like Medicaid, Medicare, health insurance subsidies, vocational rehabilitation and job training, Social Security and Supplemental Security Income, Unemployment Insurance, Section 8 and related housing assistance programs, and the Supplemental Nutrition Assistance Program. Labor standards, employment and civil rights protections, and other measures are also core to a robust agenda of economic inclusion for people with disabilities and their families. Together, these and related federal and state programs and policies empower people with disabilities to lead independent lives and to contribute and participate fully in their communities and the economy.[[193]](#endnote-193) Paid leave is an important complement to these policies, but is virtually unavailable to most households with disabilities.

Comprehensive PFML enables workers with disabilities and workers caring for a family member with a disability to stay connected to the workforce and balance competing personal, financial, and job responsibilities. By ensuring job security and promoting care and medical treatment, paid leave can help mitigate some of the disadvantages faced by workers with disabilities, working family caregivers, and their families. Beyond the scope of this paper, paid leave can also be an important tool in supporting the recruitment, retention, health, and economic well-being of direct support professionals who often play a central role in the lives of people with disabilities.[[194]](#endnote-194)

In the almost quarter-century since the FMLA was first enacted in 1993, it has become clear that more is needed to support working families—especially when those families are also dealing with serious medical conditions and significant financial burdens. A survey by the National Partnership for Women & Families found that support for paid family and medical leave is widespread.[[195]](#endnote-195) It is also bipartisan,[[196]](#endnote-196) and workers, practitioners, policymakers, and employers[[197]](#endnote-197) are all stepping up to expand access for working families in a variety of ways.[[198]](#endnote-198), [[199]](#endnote-199) Despite these changes, the 2016 National Study of Employers found that “the average amount of parental and caregiving leave provided by U.S. employers has not changed significantly since 2012.”[[200]](#endnote-200) And even though access to paid sick days has recently increased,[[201]](#endnote-201) further legislative efforts at all levels of government remain essential to widen access to PFML for workers and their families.[[202]](#endnote-202)

Needs related to a new child, one’s own health, or the health of a family member manifest in many forms and situations—only some of which are covered under the limited patchwork of existing federal and state laws governing paid and unpaid leave. To more fully address the needs of people with disabilities and their families, paid leave should reflect these realities in a number of ways:

* Allow an expanded set of family members (including family of choice) to qualify;
* Cover workers at employers of all sizes, including smaller employers and workers who are self-employed;
* Allow qualification based on a reasonable part-time work history;
* Define qualifying events to be inclusive of the full range of potential parental, medical, and caregiving needs of people with disabilities;
* Establish progressive replacement rates that near 100 percent for low-wage workers;
* Ensure continuation of health coverage during the period of leave;
* Permit intermittent use of leave to allow for periodic medically-required attention and rest;
* Permit sufficiently lengthy leave to promote positive outcomes for people with disabilities and caregivers of people with disabilities;
* Provide for job protection and be available without adverse employment consequences; and
* Include robust public outreach and education that is fully accessible to and inclusive of people with disabilities.

The U.S. has a long way to go before all workers and their families, regardless of what types of jobs they have, can access universal, equitable, and adequate paid leave. However, the positive momentum and widespread support behind paid leave is clear. Creating a comprehensive national paid leave policy that can support the employment and economic security of workers with disabilities and their families, and more broadly, their communities, may have far reaching benefits. For example, it may help mitigate gender and race inequities in family-work expectations and arrangements. And by improving labor market outcomes[[203]](#endnote-203) and business productivity,[[204]](#endnote-204) comprehensive paid leave can increase economic growth. As a result, a comprehensive paid leave policy designed with people with disabilities and caregivers in mind would help advance national goals ranging from growing economic prosperity and achieving equity, to strengthening families and expanding freedom for workers and their families.

# **Appendix**

All estimates, unless otherwise noted, are based on Georgetown Center on Poverty and Inequality (GCPI) analysis using a five-year pool of American Community Survey (ACS) data (2011-2015) and define an individual as having a disability if they meet at least one of the following criteria: having a U.S. Department of Veterans Affairs service-connected disability rating greater than zero; reporting cognitive difficulty, ambulatory difficulty, independent living difficulty, self-care difficulty, vision difficulty, or hearing difficulty; or receiving Social Security or Supplemental Security Income while under the age of 65.

[Start of Exhibit 1]

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **EXHIBIT 1. People with disabilities in the United States, 2015** | | | | | |
|  | U.S. population | | Children (5-17 years old) | Working age adults (18-64 years old) | Seniors (65+ years old) |
|  | Number of individuals with disabilities | Percentage of population that have disabilities | Number of children with disabilities | Number of working age adults with disabilities | Number of seniors with disabilities |
| Overall | 47,100,000 | 15.9% | 3,700,000 | 26,300,000 | 17,400,000 |
| By gender | | | | | |
| Male | 23,500,000 | 16.1% | 2,200,000 | 13,700,000 | 7,700,000 |
| Female | 23,600,000 | 15.6% | 1,500,000 | 12,600,000 | 9,700,000 |
| By race/ethnicity | | | | | |
| African American | 7,000,000 | 19.4% | 700,000 | 4,700,000 | 1,200,000 |
| American Indian and Alaska Native | 400,000 | 22.1% | 40,000 | 300,000 | 100,000 |
| Asian American and Pacific Islander | 1,300,000 | 8.4% | 90,000 | 700,000 | 600,000 |
| Hispanic/Latino | 5,500,000 | 11.2% | 800,000 | 3,000,000 | 1,400,000 |
| White | 31,800,000 | 17.0% | 2,000,000 | 16,600,000 | 13,400,000 |
| Mixed | 1,000,000 | 16.0% | 200,000 | 700,000 | 200,000 |
| By age group | | | | | |
| Ages 5-10 | 1,200,000 | 4.9% | 1,200,000 | X | X |
| Ages 11-17 | 2,100,000 | 7.2% | 2,100,000 | X | X |
| Ages 18-24 | 2,300,000 | 7.1% | X | 2,300,000 | X |
| Ages 25-34 | 3,500,000 | 7.9% | X | 3,500,000 | X |
| Ages 35-44 | 4,200,000 | 10.0% | X | 4,200,000 | X |
| Ages 45-54 | 7,100,000 | 15.8% | X | 7,100,000 | X |
| Ages 55-64 | 9,200,000 | 23.1% | X | 9,300,000 | X |
| Ages 65-74 | 7,000,000 | 27.7% | X | X | 7,000,000 |
| Ages 75+ | 10,400,000 | 53.0% | X | X | 10,400,000 |

[End of Exhibit 1]

[Start of Exhibit 2]

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **EXHIBIT 2. Employment and labor force outcomes for working-age adults with disabilities, Between ages 18 and 64, 2015** | | | | | | | | |
|  | *Working-age adults with a disability* | | | | *Working-age adults without a disability* | | | |
|  | Labor force participation rate | Unemployment rate | Percent of labor force participants that work full-time | Percent of labor force participants that work part-time | Labor force participation rate | Unemployment rate | Percent of labor force participants that work full-time | Percent of labor force participants that work part-time |
| Overall | 39.9% | 16.2% | 52.7% | 37.9% | 81.3% | 7.2% | 67.5% | 28.9% |
| By gender |  |  |  |  |  |  |  |  |
| Male | 43.2% | 16.7% | 57.6% | 33.4% | 86.4% | 8.4% | 73.2% | 23.5% |
| Female | 36.4% | 17.4% | 46.4% | 43.7% | 76.2% | 6.9% | 61.4% | 35.0% |
| By Race/Ethnicity | | | | | | | | |
| African American | 34.1% | 25.0% | 46.5% | 37.2% | 73.2% | 13.6% | 62.6% | 30.0% |
| American Indian and Alaska Native | 34.4% | 22.0% | 48.4% | 38.1% | 76.3% | 12.5% | 60.9% | 32.3% |
| Asian American and Pacific Islander | 44.1% | 13.0% | 55.6% | 35.8% | 79.1% | 6.2% | 69.2% | 27.2% |
| Hispanic/Latino | 41.2% | 14.3% | 50.9% | 39.2% | 79.7% | 8.9% | 64.2% | 31.4% |
| White | 41.2% | 14.7% | 54.7% | 37.7% | 82.7% | 6.0% | 69.5% | 28.0% |
| Mixed | 41.3% | 20.0% | 45.2% | 42.9% | 85.0% | 12.0% | 59.8% | 35.5% |
| By age group |  |  |  |  |  |  |  |  |
| Ages 18-24 | 45.9% | 30.0% | 20.8% | 62.6% | 69.0% | 14.9% | 33.6% | 59.2% |
| Ages 25-34 | 50.3% | 22.2% | 46.8% | 41.9% | 84.9% | 7.8% | 69.1% | 27.3% |
| Ages 35-44 | 46.6% | 15.0% | 55.1% | 35.2% | 86.5% | 6.0% | 74.9% | 22.3% |
| Ages 45-54 | 41.0% | 13.8% | 59.0% | 32.6% | 87.7% | 5.6% | 76.1% | 21.3% |
| Ages 55-64 | 30.7% | 10.7% | 59.9% | 33.6% | 74.5% | 4.9% | 73.0% | 24.5% |

[End of Exhibit 2]

[Start of Exhibit 3]

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **EXHIBIT 3. Poverty and near poverty rates by disability status, 2015** | | | | | | |
|  | *Individuals with disabilities* | | | *Individuals without disabilities* | | |
|  | At or below the Official Poverty Measure (OPM) | At or below 150% of the OPM | At or below 200% of the OPM | At or below the OPM | At or below 150% of the OPM | At or below 200% of the OPM |
| Overall | 26.3% | 39.2% | 50.0% | 15.5% | 23.9% | 32.6% |
| By gender | | | | | | |
| Male | 23.9% | 35.7% | 45.8% | 14.9% | 22.8% | 31.3% |
| Female | 28.7% | 42.8% | 53.9% | 16.1% | 25.0% | 33.8% |
| By race/ethnicity | | | | | | |
| African American | 39.2% | 54.2% | 64.6% | 26.8% | 38.1% | 48.5% |
| American Indian and Alaska Native | 36.8% | 51.9% | 63.0% | 28.2% | 40.3% | 51.1% |
| Asian American and Pacific Islander | 22.1% | 33.6% | 42.7% | 13.9% | 21.2% | 28.7% |
| Hispanic/Latino | 33.2% | 49.3% | 61.5% | 24.1% | 38.8% | 51.7% |
| White | 22.1% | 34.0% | 44.5% | 10.9% | 17.0% | 24.2% |
| Mixed | 32.7% | 46.3% | 56.5% | 19.6% | 28.5% | 37.3% |
| By age group | | | | | | |
| Ages 5-10 | 38.3% | 52.6% | 63.1% | 23.2% | 35.2% | 45.6% |
| Ages 11-17 | 30.9% | 44.9% | 56.0% | 19.9% | 30.7% | 40.6% |
| Ages 18-24 | 37.6% | 50.1% | 60.3% | 32.5% | 42.5% | 52.0% |
| Ages 25-34 | 34.8% | 47.0% | 56.9% | 16.2% | 25.2% | 34.8% |
| Ages 35-44 | 33.9% | 47.0% | 56.7% | 12.3% | 20.1% | 28.5% |
| Ages 45-54 | 31.1% | 44.0% | 53.7% | 8.7% | 14.3% | 21.0% |
| Ages 55-64 | 24.5% | 37.2% | 47.3% | 7.5% | 12.5% | 18.5% |
| Ages 65-74 | 16.2% | 28.3% | 39.1% | 7.0% | 14.3% | 22.4% |
| Ages 75+ | 20.8% | 34.3% | 46.7% | 9.3% | 20.7% | 32.9% |
| By educational attainment | | | | | | |
| Less than high school | 37.4% | 54.2% | 66.1% | 23.7% | 36.4% | 47.5% |
| High School | 26.0% | 39.4% | 50.9% | 16.5% | 26.0% | 36.4% |
| Bachelor of Arts+ | 18.0% | 27.2% | 35.7% | 9.7% | 14.7% | 30.6% |

[End of Exhibit 3]

[Start of Exhibit 4]

|  |  |  |
| --- | --- | --- |
| **EXHIBIT 4. Median personal income for working-age adults, Between ages 18 and 64, 2015** | | |
|  | Individuals with disabilities | Individuals without disabilities |
| Overall | $12,100 | $26,000 |
| By gender |  |  |
| Male | $14,400 | $35,000 |
| Female | $10,500 | $20,400 |
| By race/Ethnicity |  |  |
| African American | $9,800 | $20,000 |
| American Indian and Alaska Native | $10,000 | $16,800 |
| Asian American and Pacific Islander | $10,900 | $25,400 |
| Latino | $10,100 | $18,000 |
| White | $13,600 | $31,600 |
| Mixed | $10,700 | $20,600 |
| By age group |  |  |
| Ages 18-24 | $6,100 | $5,200 |
| Ages 25-34 | $10,100 | $25,800 |
| Ages 35-44 | $12,000 | $35,000 |
| Ages 45-54 | $12,400 | $37,700 |
| Ages 55-64 | $15,000 | $35,600 |
| By educational attainment |  |  |
| Less than HS | $8,700 | $11,000 |
| HS | $11,000 | $20,300 |
| B.A.+ | $20,100 | $36,200 |

[End of Exhibit 4]

[Start of Exhibit 5]

|  |  |  |
| --- | --- | --- |
| **EXHIBIT 5. Economic outcomes for working-age potential caregivers,\* Between ages 18 and 64, 2015** | | |
|  | Working-age adults with additional household members with disabilities | Working-age adults with no additional household members with disabilities |
| Total | 36,000,000 | 163,000,000 |
| Labor force participation rate | 68.0% | 77.5% |
| Unemployment rate | 13.0% | 7.1% |
| Percent of labor force participants that work full-time | 57.1% | 68.2% |
| Percent of labor force participants that work part-time | 35.1% | 28.5% |
| Median personal income (annual) | $15,500 | $25,800 |
| Percent living in or near poverty |  |  |
| At or below the Official Poverty Measure (OPM) | 18.1% | 16.8% |
| At or below 150% of the OPM | 30.0% | 24.2% |
| At or below 200% of the OPM | 40.4% | 31.8% |
| \*If a working-age adult of any disability status lives in a household with one or more additional members with disabilities, they are characterized as a potential caregiver and included in this table. | | |

[End of Exhibit 5]

[Start of Exhibit 6]

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **EXHIBIT 6. Household economic characteristics, 2015** | | | | | | |
|  | **HOUSEHOLDS WITH AT LEAST ONE PERSON WITH A DISABILITY** | | | | | Households with no one with a disability |
|  | Overall | Households with one or more childrenwith a disability (5-17 years old) | Households with one or more working age adults with a disability (18-64 years old) | Households with one or more seniors with a disability (65+ years old) | Households where the household head has a disability |
| Total number of households | 33,700,000 | 3,100,000 | 19,900,000 | 13,700,000 | 23,300,000 | 83,200,000 |
| Percent of households | 28.8% | 8.2% (of households with children) | 20.7% (of households with working age adults) | 43.9% (of households with seniors) | 19.9% | 71.11% |
| Median income | $51,600 | $50,100 | $51,600 | $51,000 | $39,600 | $70,500 |
|  |  |  |  |  |  |  |
| **Percent living in or near poverty** | | |  |  |  |  |
| At or below the Official Poverty Measure (OPM) | 23.1% | 35.4% | 31.1% | 17.7% | 27.5% | 18.4% |
| At or below 150% of the OPM | 35.0% | 48.8% | 42.3% | 29.4% | 40.8% | 26.6% |
| At or below 200% of the OPM | 46.0% | 59.5% | 52.6% | 40.6% | 51.4% | 34.8% |

[End of Exhibit 6]

# **Endnotes**

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2. See Footnote 5 in Carlson, Keith-Jennings, and Chaudhry. “SNAP Provides Needed Food Assistance to Millions of People with Disabilities.” Center on Budget and Policy Priorities, 2017. [↑](#endnote-ref-2)
3. All estimates, unless otherwise noted, are based on Georgetown Center on Poverty and Inequality (GCPI) analysis using a five-year pool of American Community Survey (ACS) data (2011-2015) and define an individual as having a disability if they meet at least one of the following criteria: having a U.S. Department of Veterans Affairs service-connected disability rating greater than zero; reporting cognitive difficulty, ambulatory difficulty, independent living difficulty, self-care difficulty, vision difficulty, or hearing difficulty; or receiving Social Security or Supplemental Security Income while under the age of 65. Due to limitations of the ACS, disability status information is only available for ages five and up. All ACS public use microdata was extracted from Ruggles, Steven, et al. “Integrated Public Use Microdata Series: Version 5.0 [Machine-readable database].” USA IPUMS, Minnesota Population Center [producer and distributor], 2010. [↑](#endnote-ref-3)
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28. Developing a detailed policy proposal is beyond the scope of this report. [↑](#endnote-ref-28)
29. Disability has no agreed-upon definition in the United States. Competing definitions have at their core the existence of a physical, mental, or sensory impairment that limits basic life activities. The Census Bureau estimated that in 2010, 19 percent of the civilian noninstitutionalized population had a disability, defined as a “physical or mental impairment that affects one or more major life activities, such as walking, bathing, dressing, eating, preparing meals, doing errands alone or doing housework.” Brault, Matthew. “Americans With Disabilities: 2010.” U.S. Census Bureau, July 2012. Available at https:// [www.census.gov/library/publications/2012/demo/p70-131.html](http://www.census.gov/library/publications/2012/demo/p70-131.html). [↑](#endnote-ref-29)
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31. Working-age adults are 18-64 years old. Authors’ calculations using the American Community Survey five-year sample (2011-2015). [↑](#endnote-ref-31)
32. Authors’ calculations using the American Community Survey five-year sample (2011-2015). [↑](#endnote-ref-32)
33. Vallas, Rebecca and Shawn Fremstad. “A Fair Shot for Workers with Disabilities.” Center for American Progress, 28 January, 2015. Available at <https://www.americanprogress.org/issues/poverty/reports/2015/01/28/105520/a-fair-shot-for-workers-with-disabilities/>. [↑](#endnote-ref-33)
34. “Thirty-two percent of adults report that their income varies to some degree from month to month, and 43 percent report that their monthly expenses vary to some degree. Forty-two percent of those with volatile incomes or expenses say that they have struggled to pay their bills at times because of this volatility.” “Report on the Economic Well-Being of U.S. Households in 2015.” Board of Governors of the Federal Reserve System, May 2016. Available at <https://federalreserve.gov/2015-report-economic-well-being-us-households-201605.pdf>. [↑](#endnote-ref-34)
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36. Carlson, Keith-Jennings, and Chaudhry. “SNAP Provides Needed Food Assistance to Millions of People with Disabilities.” Center on Budget and Policy Priorities, 2017. [↑](#endnote-ref-36)
37. See, for example, Axelrad, Daniel, et al. “America’s Children and the Environment.” U.S. Environmental Protection Agency, Third Edition, January 2013. Available at <https://www.epa.gov/sites/production/files/2015-06/documents/ace3_2013.pdf>. See also Collins, Mary B., Ian Munoz, and Joseph JaJa. “Linking ‘Toxic Outliers’ to Environmental Justice Communities.” Environmental Research Letters, 11(1), 26 January, 2016. Available at <http://iopscience.iop.org/article/10.1088/1748-9326/11/1/015004/pdf>. [↑](#endnote-ref-37)
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45. Authors’ calculations using the American Community Survey (ACS) five- year sample (2011-2015). Our unemployment calculations may yield higher numbers than the Bureau of Labor Statistics (BLS) official unemployment numbers due to rounding errors and because the BLS bases their rates on the Current Population Survey (CPS), rather than the ACS, which we use. The ACS may have higher unemployment numbers than the CPS by 25-30 percent. [↑](#endnote-ref-45)
46. Oberoi, Ashmeet Kaur, et al. “Employment and Outcomes among African American and White Woman with Disabilities: Examining the Inequalities.” Women, Gender, and Families of Color, 3(2):144-164, Fall 2015. Available at <http://jstor.org/stable/10.5406/womgenfamcol.3.2.0144?seq=1-page_scan_tab_contents>. [↑](#endnote-ref-46)
47. Even though people with disabilities were less likely to be employed than people without disabilities across all educational backgrounds, among people with disabilities, employment rates increase from 9 percent to 26.2 percent as individual educational attainment increases. Data are for the civilian noninstitutional population age 25 or older. “Persons with a Disability: Labor Force Characteristics Summary.” Bureau of Labor Statistics, U.S. Department of Labor, 21 June, 2017. Available at <https://www.bls.gov/news.release/disabl.nr0.htm>. [↑](#endnote-ref-47)
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55. For authors’ calculations, an individual is defined as a full-time worker if they participate in the labor force and usually worked at least 35 hours a week for at least 48 weeks in 2015; an individual is characterized as a part-time worker if they usually worked at least one but less than thirty-five hours per week or for less than 48 weeks in 2015. Authors’ calculations using the American Community Survey five-year sample (2011-2015) and “Persons with a Disability: Labor Force Characteristics Summary.” Bureau of Labor Statistics, U.S. Department of Labor, 2017. [↑](#endnote-ref-55)
56. Authors’ calculations using the American Community Survey five-year sample (2011-2015). [↑](#endnote-ref-56)
57. Ibid. [↑](#endnote-ref-57)
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59. She, Peiyun and Gina A. Livermore. “Long-Term Poverty and Disability Among Working-Age Adults.” Journal of Disability Policy Studies, 19(4)2009. Available at <http://journals.sagepub.com/doi/abs/10.1177/1044207308314954>. [↑](#endnote-ref-59)
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61. “Caregiving in the U.S.” AARP Public Policy Institute and National Alliance or Caregiving, June 2015. Available at <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>. [↑](#endnote-ref-61)
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64. Though a significant amount of unpaid caregiving support does occur for people in both institutional and noninstitutional group quarters, as well as for individuals who do not live in the same household as the caregiver, we are looking at households from a shared finances perspective, and the Census data do not identify if a caregiving relationship is present or not in a household or across households and group quarters. For an example of unpaid caregiving in group quarters, see pp. 11, Figure 4 from Hunt, Gail Gibson, et al. “Caregiving in the U.S. 2015—Executive Summary.” AARP Public Policy Institute and National Alliance for Caregiving, June 2015. Available at [http://www.caregiving.org/wp-content/uploads/2015/05/2015\_CaregivingintheUS\_ Executive-Summary-June-4\_WEB.pdf](http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_%20Executive-Summary-June-4_WEB.pdf). Original data analysis in this report uses households rather than families because the American Community Survey definition of households is more inclusive, as defined by the Census Bureau. A household “includes all the people who occupy a housing unit …A housing unit is a house, an apartment, a mobile home, a group of rooms, or a single room that is occupied (or if vacant, is intended for occupancy) as separate living quarters. Separate living quarters are those in which the occupants live separately from any other people in the building and which have direct access from the outside of the building or through a common hall. The occupants may be a single family, one person living alone, two or more families living together, or any other group of related or unrelated people who share living arrangements.” A family “consists of a householder and one or more other people living in the same household who are related to the householder by birth, marriage, or adoption. All people in a household who are related to the householder are regarded as members of his or her family.” For more information, see “American Community Survey and Puerto Rico Community Survey 2015 Subject Definitions.” U.S. Census Bureau, retrieved July 2017. Available at <https://www2.census.gov/programs-surveys/acs/tech_docs/subject_definitions/2014_ACSSubjectDefinitions.pdf>. [↑](#endnote-ref-64)
65. Authors’ calculations using the American Community Survey five-year sample (2011-2015). [↑](#endnote-ref-65)
66. Ibid. [↑](#endnote-ref-66)
67. Ibid. [↑](#endnote-ref-67)
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    at <https://www.census.gov/data/tables/2013/demo/wealth/wealth-asset-ownership.html>. [↑](#endnote-ref-68)
69. “Table 1. Median Value of Assets for Households, by Type of Asset Owned and Selected Characteristics: 2013.” U.S. Census Bureau, 2013. Available at <https://www.census.gov/data/tables/2013/demo/wealth/wealth-asset-ownership.html>. [↑](#endnote-ref-69)
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180. “Fact Sheet #28C: The definition of “parent” as it applies to an individual who stood in loco parentis to an employee for FMLA “eldercare” protections.” U.S. Department of Labor, Wage and Hour Division, July 2015. Available at <https://www.dol.gov/whd/regs/compliance/whdfs28C.pdf>. [↑](#endnote-ref-180)
181. Bowman, et al. “Making Paid Leave Work for Every Family.” Center for American Progress, et al., 2016. [↑](#endnote-ref-181)
182. Gallagher Robbins, Katherine, et al. “People Need Paid Leave Policies that Cover Chosen Family.” Center for American Progress, 30 October, 2017. Available at https://www.americanprogress.org/issues/poverty/reports/2017/10/30/441392/people-need-paid-leave-policies-that-cover-chosen-family/. [↑](#endnote-ref-182)
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184. Donovan. “Paid Family Leave in the United States.” Congressional Research Service, R44835, 2017. [↑](#endnote-ref-184)
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