



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

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CCD Principles for Paid Leave

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. In response to recent Congressional interest in paid parental, medical, and caregiving leave, CCD has convened an Ad Hoc Paid Leave Task Force. Despite recent expansions of paid leave in states and changes to the federal system, CCD believes that a national paid leave program is necessary.

If structured correctly, a national paid leave program would address several crucial challenges for people with disabilities and their families. People with disabilities face barriers to work, some related to their disability requiring substantial care and others related to their own caregiving responsibilities. The protections of the Americans with Disabilities Act provide some protections, but many people with disabilities are still asked to choose between their jobs and taking care of themselves or those who rely on them for crucial care needs. For Black, Indigenous, and people of color (BIPOC) with disabilities, the racial wealth gap exacerbates the lack of resources available to plan for and absorb the effects of a serious personal or family medical issue, making paid leave even more important.¹ A recent survey by the Bipartisan Policy Center found that 16% of Latino and 13% of Black adults have left the workforce to provide care for an adult family member during the pandemic. A national paid leave program would not only provide medical leave for people with disabilities and caregiving leave for family members, but would also ensure that people with disabilities could take parental and caregiving leave themselves. Even more importantly, it would give workers with disabilities and family member workers “the freedom to balance competing personal, financial, and workplace responsibilities.”¹

Over the past year, the COVID pandemic has highlighted exactly how important it is to have a national paid leave program. Millions of families suddenly found themselves needing to isolate for two weeks or take leave to care for family members. Many people with disabilities lost

¹ <https://www.nationalpartnership.org/our-work/resources/economic-justice/paid-leave/called-to-care-a-racially-just-recovery-demands-paid-family-and-medical-leave.pdf>

access to services and family caregivers scrambled to fill gaps in care, many without paid leave.² Children with disabilities relied on family caregivers not only for lost services, but for school demands as well. The essential work force of women of color that provides frontline disability services faced heightened risk of COVID and frequently lacked paid leave, despite needing to isolate to protect those they serve. BIPOC with disabilities have disproportionately died and faced huge economic impacts from the pandemic, in addition to facing these disability specific challenges. But each of these examples is something that happened to some families every day before the pandemic and will continue to happen after the pandemic is over. We need a permanent, national paid leave program to better support our care infrastructure.

Research suggests that in order to be useful for people with disabilities, especially black, Indigenous and people of color with disabilities, paid leave must be inclusive, comprehensive, and flexible.² In addition, a paid leave program must be thoughtfully implemented and carefully integrated alongside existing programs and policies. Given these crucially important policy issues for people with disabilities, the CCD Working Group has developed principles to guide assessment of paid leave proposals from a disability perspective:

A paid leave program must be inclusive.

A paid leave program must provide medical, parental, and caregiving leave. People with disabilities have, by definition, health conditions. But people with disabilities are also parents and caregivers and must be able to access all three kinds of leave. Some adults with disabilities also rely on caregivers, as do all children with disabilities. These caregivers must be able to access leave as necessary. Research from the National Alliance for Caregiving shows that over 50 percent of family caregivers are dependent on hourly wages for their income, suggesting that unpaid time they take off to provide care further threatens their economic stability. Sixty two percent of caregivers working over 30 hours or more per week say paid leave would help them financially.

A paid leave program must have a broadly inclusive definition of family and must expand the list of those eligible to take leave and receive care to, at a minimum, include siblings, grandparents, aunts, uncles, cousins, nieces, nephews, grandchildren, and domestic partners. People with disabilities are more likely to be caregivers for chosen family than people without disabilities, as are LGBTQ+ people with disabilities, making coverage of a broad definition of family very important.³ In addition, people with disabilities often receive caregiving from individuals not currently covered by FMLA's definition of family. For example, siblings are not covered by the current FMLA definition of family, unless they are determined to be standing *in loco parentis*, a complicated interpretation by the Department of Labor that is frequently not honored by employers. If a sibling requires leave in response to an unexpected crisis, they may not be able to convince their employers they fall under this interpretation or have time to go through a complicated legal process. State paid leave programs have recognized this need and

² <https://thearc.org/care-during-covid-19-an-essential-working-familys-story/>

four included a broader definition of family in their programs.

In addition, best practices in disability service provision emphasize the importance of natural supports, including chosen family and other unrelated supporters who nonetheless play a crucial role in providing unpaid caregiving to a person with a disability who has welcomed them into their life. Siblings, grandparents, grandchildren, and other family members currently excluded by FMLA need a clear and comprehensive definition of family included in statute. This is particularly important for non-traditional families.

A paid leave program must be available to all workers, regardless of employer size, including part-time workers and self-employed workers. People with disabilities and their caregivers, like everyone else, will need paid leave regardless of employer size, and all workers should be covered by a paid leave program. Currently, “low-paid workers are less likely to have access to paid leave than those with higher pay.” People with disabilities are more likely, on average, to work in low-wage, part-time, non-managerial jobs, especially Black, Indigenous, and people of color with disabilities and it is particularly important for people with disabilities that all employees are covered by federal paid family and medical leave.⁴

People with disabilities receive care from family members and from paid caregivers, who are often low-wage workers and those low-wage workers should also have access to paid leave. Many caregivers can work only part-time due to their caregiving responsibilities. Currently, 92 percent of part-time workers have no access to paid leave.⁵ For a person with a disability or a caregiver, that part-time job may be the only job they can work to accommodate their disability or caregiving responsibilities, and the wages of that job are often crucial for economic security and their families. All workers must be covered by a paid leave program. And paid leave must easily follow an employee from job to job, without burdensome paperwork or other requirements.

A paid leave program must be comprehensive.

The wage replacement rate must be progressive and must be sufficient to ensure that people can afford to take leave. A paid leave program will not be effective if the wage replacement rate is so low that individuals and families, and particularly low-income individuals and families, cannot afford to take leave. For low-income individuals, this is particularly important and research indicates that “wage replacement levels were a barrier to participation for low-income households” in California until they adjusted the levels.⁶ Any paid leave proposal must replace wages with a progressive structure, with full wage replacement for low income individuals and households. This would include ensuring rapid wage replacement to ensure that people who cannot afford to do so do not have to go without a paycheck. Similarly, there should not be a required waiting period of unpaid leave before claiming benefits. A paid leave program must work for people living in poverty in order to work for people with disabilities.

A paid leave program must ensure job protection and include anti-retaliation provisions. Unfortunately, disability discrimination in the workplace is prevalent. In 2018, people with

disabilities accounted for 32 percent of all charges filed with the Equal Employment Opportunity Commission.⁷ Just over half of all charges were retaliation charges. BIPOC with disabilities also face compounding racial discrimination in addition to disability discrimination and these protections are even more important to them. Job protection and anti-retaliation provisions are crucial protections that must be a part of any paid leave program.

A paid leave program must ensure continued access to employer-provided benefits, especially health insurance. Currently, the FMLA guarantees continued access to employer health insurance benefits. This must be carried over into a new paid leave program. But since a new paid leave program will be more inclusive of part time and contract workers, other forms of compensation designed to assist employees pay for health insurance must also be maintained during leave.

A paid leave program must be flexible.

A paid leave program must allow for intermittent use. People with disabilities and caregivers for people with disabilities, more than others, may require intermittent use of leave over the course of a year. For example, leave should be flexible to accommodate bi-weekly physical therapy sessions following a car accident, a temporary increase in seizures in a person with epilepsy due to medication changes, or intensive mental health sessions in times of crisis. It should also allow caregivers to take their loved ones to chemotherapy or other appointments intermittently.

The duration of leave provided must be sufficient to ensure that people have time to recover from serious medical conditions, provide care, or bond with a child. People with disabilities frequently utilize the Family Medical Leave Act (FMLA), which is limited to 12 weeks of leave, and receive leave as a reasonable accommodation under the Americans with Disabilities Act. Different situations require different lengths of leave and we would expect the program to be flexible enough to deal this variation. In addition, we expect the full duration of leave to be available for all leave purposes. A worker should retain the right to 12 weeks of unpaid leave under the FMLA regardless of whether the employee has or will also take employer provided paid leave for an FMLA-qualifying event.

A paid leave program must respond to unpredictable disabilities and chronic conditions. While some reasons for leave are predictable and can be planned around, many are unexpected and difficult to plan for. For some disabilities and chronic conditions, this unpredictability is a part of the disability or condition. Leave must be available promptly to respond to the unpredictability of an asthma attack, for example, and readily available without pre-scheduling requirements.

A paid leave program must be easy to use. The disability community is all too familiar with complex federal programs, such as Medicaid and Social Security. The creation of a new federal program is an opportunity to ensure that all individuals, including those with cognitive disabilities, can access them. All processes and materials must be accessible. People with

disabilities, and BIPOC with disabilities, must be involved in building the new system and must be clear target of outreach and engagement as the program is being rolled out.

A paid leave program must be thoughtfully implemented and carefully integrated alongside existing programs and policies.

A paid leave program should be created with new funding sources and not be carved out of or borrowed from funds dedicated to Social Security or other crucial federal safety net programs.

Our Social Security system is a foundation of economic security for workers and their families in the event of a worker's retirement, disability, or death. Social Security represents a promise to U.S. workers that has been built up and honored for over 80 years, and it should not be limited or cut. Expanding access to paid leave is an important goal for all workers, including people with disabilities and their families. However, proposals to fund paid leave out of workers' future Social Security benefits would break the promise of Social Security and should be rejected. Likewise, efforts to repurpose child- or low-income tax credits, which are designed for other policy purposes, should be rejected as a means to pay for leave. Similarly, people should be able to utilize paid leave without jeopardizing their eligibility for other federal safety net programs.

A paid leave program must have sufficient administrative resources and not burden the agency from which it is administered. For instance, the Social Security Administration (SSA) currently lacks the resources to operate and strengthen its existing core programs. From 2010 to 2019, SSA's operating budget shrank by nearly 11 percent while workloads rose.⁸ As a result, customer service has been eroded across the agency. Today, more than 600,000 people are waiting an average of nearly 500 days for a hearing before an SSA Administrative Law Judge. These historic waits lead to extreme hardship: while awaiting a hearing, many struggle to pay rent or meet basic needs. Some lose their homes or go into bankruptcy, and in Fiscal Year 2017 approximately 10,000 people died while waiting for a hearing.⁹ SSA cannot afford to repurpose existing limited resources to implement a new program and even with its own funding, any new program would further burden the agency, creating additional and unacceptable delays. Other agencies might face similar burdens and this should be part of the analysis of where a new paid leave program should be placed. The new program will require new mandatory funding to ensure successful implementation wherever it is located.

A paid leave program must be thoughtfully incorporated into the system of federal employment laws that exist today, with a carefully structured transition. Currently, people with disabilities rely on the FMLA and the ADA to ensure that they have access to the medical, parental, and caregiving leave they require. For some families, the FMLA was the only reason they have "a chance to take care of their loved ones without bearing the repercussions of losing out on employment or health insurance."¹⁰ And the reasonable accommodations guaranteed by the ADA frequently mean the difference between a person with a disability being able to work or not. These protections must be maintained and complement the new protections of a paid leave program. A crucial part of this is ensuring that the transition to a new paid leave program is carefully structured to not jeopardize current protections. People with disabilities

cannot be required to use paid leave instead of receiving a reasonable accommodation, such as a flexible schedule or job restructuring. Privacy protections in the ADA that do not require extensive detailing of a medical condition must be carried over to ensure that people with disabilities do not have to disclose more than necessary to employers. Similarly, the Health Insurance Portability and Accountability Act protections for the care recipient must be maintained.

The undersigned members of CCD endorse these principles and express our support for the creation of a flexible, comprehensive, and inclusive paid leave policy. For more information, contact the CCD Paid Leave Task Force co-chair (Bethany Lilly, lilly@thearc.org).

Sincerely,

Autistic Self Advocacy Network
Center for Public Representation
Division for Early Childhood of the Council for Exceptional Children (DEC)
Epilepsy Foundation
National Alliance for Caregiving
National Organization of Social Security Claimants' Representatives
National Respite Coalition
RespectAbility
The Arc of the United States

¹ GEORGETOWN CENTER ON POVERTY AND INEQUALITY AND THE ARC, SECURITY & STABILITY: PAID FAMILY LEAVE AND ITS IMPORTANCE FOR PEOPLE WITH DISABILITIES, 7 (2017), https://thearc.org/wp-content/uploads/forchapters/Georgetown_PFML-report_Dec17.pdf.

² *Id.*

³ CENTER FOR AMERICAN PROGRESS, PEOPLE NEED PAID LEAVE POLICIES THAT COVER CHOSEN FAMILY (2017) (“Among people with disabilities, 42 percent reported taking time off to care for chosen family, compared with 30 percent of people without disabilities.”), <https://cdn.americanprogress.org/content/uploads/2017/10/26135206/UnmetCaregivingNeed-brief.pdf>.

⁴ GEORGETOWN AND THE ARC, *supra* note 1.

⁵ DEPARTMENT OF LABOR, BUREAU OF LABOR STATISTICS, NATIONAL COMPENSATION SURVEY: EMPLOYEE BENEFITS IN THE UNITED STATES, Table 31 (March 2020), <https://www.bls.gov/ncs/ebs/benefits/2020/employee-benefits-in-the-united-states-march-2020.pdf>.

⁶ NATIONAL PARTNERSHIP FOR WOMEN AND FAMILIES, PAID FAMILY AND MEDICAL LEAVE POLICY METRICS (2018), <http://www.nationalpartnership.org/our-work/resources/workplace/coalition/paid-family-and-medical-leave-policy-metrics.pdf>.

⁷ U.S. EQUAL EMPLOYMENT OPPORTUNITY COMMISSION, CHARGE STATISTICS (2019), <https://www.eeoc.gov/eeoc/statistics/enforcement/charges.cfm>.

⁸ CENTER ON BUDGET AND POLICY PRIORITIES, SENATE BILL WOULD CUT SOCIAL SECURITY OPERATIONS AGAIN (2019), <https://www.cbpp.org/blog/senate-bill-would-cut-social-security-operations-again>.

⁹ The Washington Post, *597 days. And still waiting.* (2017), <https://www.washingtonpost.com/sf/local/2017/11/20/10000-people-died-waiting-for-a-disability-decision-in-the-past-year-will-he-be-next/>.

¹⁰ THE ARC, HOW THE FAMILY AND MEDICAL LEAVE ACT SAVED MY FAMILY (2018), <https://thearc.org/family-medical-leave-act-saved-family/>.