



For people with intellectual  
and developmental disabilities

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Thank you for the opportunity to respond to this request for information. We applaud the working group and its members for their leadership and for continuing to pursue solutions on this critical issue. I write on behalf of The Arc of the United States, a national organization dedicated to advocating for the rights and well-being of individuals with intellectual and developmental disabilities (IDD). The Arc of the United States has nearly 600 state and local chapters across the United States. These chapters provide a wide range of services for people with intellectual and developmental disabilities (IDD), including individual and systems advocacy, public education, family support, systems navigation, support coordination services, employment, housing, support groups, and recreation. The Arc chapters are committed to improving the lives of people with IDD and their families.

***Access to paid leave is a critical issue for both people with disabilities who receive care and people with or without disabilities who provide supports and services to them.***

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.<sup>1</sup> 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.<sup>2</sup> 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. Research continually shows that paid leave supports health, including improved infant and child development,<sup>3</sup> increased breastfeeding rates,<sup>4</sup> reduced infant

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<sup>1</sup> “Table 32. Leave Benefits: Access, Civilian Workers, March 2016.” U.S. Bureau of Labor Statistics, March 2016. Available at <https://www.bls.gov/ncs/ebs/benefits/2016/ownership/civilian/table32a.pdf>.

<sup>2</sup> 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/>

<sup>3</sup> Brito, N. H. et al. (2022). Paid maternal leave is associated with infant brain function at 3 months of age. *Child Development*, 93, 1030–1043. <https://doi.org/10.1111/cdev.13765>; Kozak, K. et al. (2021), Paid maternal leave is associated with better language and socioemotional outcomes during toddlerhood. *Infancy*, 26: 536-550. <https://doi.org/10.1111/infa.12399>.

<sup>4</sup> Pac J. et al., Paid family leave and parental investments in infant health: Evidence from California. *Econ Hum Biol.* 2023 Dec;51:101308. doi: 10.1016/j.ehb.2023.101308; Perry et al., Association Between State Paid Family and Medical Leave and Breastfeeding, Depression, and Postpartum Visits. *Obstetrics & Gynecology* 143(1):p 14-22, January 2024. | DOI: 10.1097/AOG.0000000000005428.

mortality,<sup>5</sup> improved maternal health,<sup>6</sup> better ability to manage and afford cancer treatment,<sup>7</sup> and reduced occupational injuries,<sup>8</sup> all of which are issues that touch individuals with disabilities and those that provide them care.

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.<sup>9</sup> 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.<sup>10</sup> 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).<sup>11</sup> With universal access to paid leave, more caregivers would be able to take the time they needed to care for their loved one without sacrificing their job.

***The Covid-19 pandemic exacerbated an already significant crisis of Direct Support Professionals (DSPs), who provide supports and services to individuals with disabilities.***

According to a recent survey by ANCOR, 83% of providers are turning away new referrals because they do not have enough support workers. Additionally, 63% of providers are discontinuing programs and services because of the lack of DSPs.<sup>12</sup> When DSPs are unavailable to provide supports and services to individuals with I/DD, unpaid family caregivers are often filling in the gaps. A universal paid leave program would provide flexibility and relief to care givers who are providing care for a loved one during a period of time.

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<sup>5</sup> Chen, F. (2023) Does paid family leave save infant lives? Evidence from California's paid family leave program. *Contemporary Economic Policy*, 41(2), 319–337. <https://doi.org/10.1111/coep.12589>; Heymann, J. et al. Creating and using new data sources to analyze the relationship between social policy and global health: the case of maternal leave. *Public Health Rep.* 2011 Sep-Oct;126 Suppl 3(Suppl 3):127-34. doi: 10.1177/00333549111260S317.

<sup>6</sup> Mandal, B. The Effect of Paid Leave on Maternal Mental Health. *Matern Child Health J* 22, 1470–1476 (2018). <https://doi.org/10.1007/s10995-018-2542-x>; Van Niel MS et al. The Impact of Paid Maternity Leave on the Mental and Physical Health of Mothers and Children: A Review of the Literature and Policy Implications. *Harv Rev Psychiatry*. 2020 Mar/Apr;28(2):113-126. doi: 10.1097/HRP.000000000000246. PMID: 32134836.

<sup>7</sup> Mandal, B. The Effect of Paid Leave on Maternal Mental Health. *Matern Child Health J* 22, 1470–1476 (2018). <https://doi.org/10.1007/s10995-018-2542-x>; Van Niel MS et al. The Impact of Paid Maternity Leave on the Mental and Physical Health of Mothers and Children: A Review of the Literature and Policy Implications. *Harv Rev Psychiatry*. 2020 Mar/Apr;28(2):113-126. doi: 10.1097/HRP.000000000000246. PMID: 32134836.

<sup>8</sup> Asfaw A et al. Paid sick leave and nonfatal occupational injuries. *Am J Public Health*. 2012 Sep;102(9):e59-64. doi: 10.2105/AJPH.2011.300482. Epub 2012 Jun 21.

<sup>9</sup> “Caregiving in the U.S.” AARP Public Policy Institute and National Alliance of Caregiving, June 2015. Available at <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>.

<sup>10</sup> Anderson, Lynda, et al. “2010 FINDS National Survey: Family and Individual Needs for Disability Supports.” *The Arc*, May 2011. Available at <http://www.thearc.org/document.doc?id=3673>.

<sup>11</sup> Calculations using the American Community Survey five-year sample (2011-2015)

<sup>12</sup> *The State of America's Direct Support Workforce Crisis 2022*. Alexandria, VA: ANCOR, 2022.

Any paid leave program should ensure an inclusive definition of “family.” 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.<sup>13</sup> The FMLA definition that is often utilized in employer-based or state paid leave programs does not include leave for siblings who are providing care. As the large “Baby Boomer” generation grows older, more siblings are becoming primary caregivers for their sibling with disabilities. Additionally, 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.<sup>14</sup> A definition of “family” that is representative of extended and chosen families is crucial for a universal paid leave program to support people with disabilities and their caregivers.

***State leadership has demonstrated the policy parameters working families need.***

Years of experience at the state level have generated important policy best practices that should be reflected in a federal paid leave program, including:

- **Purposes:** A federal paid leave program should cover workers’ own serious health conditions, parental bonding, caregiving for seriously ill loved ones, needs in relation to military deployment, and safe leave to address sexual and domestic violence.
- **Family definition:** A federal paid leave program should have an inclusive family definition, ensuring that workers can care for all those they consider family, including loved ones to whom they may not have a legal or biological relationship.
- **Wage replacement:** A federal paid leave program should ensure that the wage replacement rate (the percentage of their own income workers receive while on leave) is high enough that workers can afford to use the benefit, particularly for low-income workers.
- **Duration:** A federal paid leave program must guarantee at least twelve weeks of paid leave.
- **Job protection:** A federal paid leave program must protect workers’ jobs, ensuring that they can return to work following leave and can use their rights without retaliation or interference.
- **Universal coverage:** A federal paid leave program must cover all workers, including employees and independent contractors, part-time and full-time workers, and public and private sector workers, regardless of industry or employer size.

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<sup>13</sup> Fremstad, Shawn and Melissa Boteach. “Valuing All Our Families: Progressive Policies that Strengthen Family Commitments and Reduce Family Disparities.” Center for American Progress, 12 January 2015. Available at <https://www.americanprogress.org/issues/poverty/reports/2015/01/12/104149/valuingall-our-families/>.

<sup>14</sup> As of 2014. Bowman, Moira, et al. “Making Paid Leave Work for Every Family.” Center for American Progress, et al., December 2016. Available at <http://forwardtogether.org/assets/files/lgbtpaidleave-report.pdf>

***Funding must be sufficient and sustainable.***

There are many viable options for raising the funds to support a comprehensive paid leave program. Regardless of which option policymakers choose, a workable paid leave program requires sustainable, reliable long-term funding at a level sufficient to support the benefits workers need.

At the same time, a federal paid leave program should not reduce funding to other programs working families and individuals with disabilities rely on. For example, paid leave should not be paid for by taking money out of Social Security or disability benefits, harming today's retirees and undermining retirement security for the future. Progress on paid leave means protections that complement existing supports, not false choices.

**Conclusion**

Thank you again for the opportunity to provide this information. We look forward to continuing to work with you to make paid leave a reality for all Americans. If you have any questions, please contact me at [linscott@thearc.org](mailto:linscott@thearc.org).

Sincerely,

*Robyn Linscott*

Director of Education and Family Policy  
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