

Data Highlight

What Do NCI-IDD Data Tell Us About the Proportion of Family Care Givers Who Are Being Paid to Provide Support? *1



According to the results of the 2021-2022 Adult Family Survey (AFS), about one in two (1 in 2) respondents to the AFS reported they or someone else in the family was paid by the IDD agency to provide services to their family member. However, states ranged from 12% of respondents in Georgia to 90% in Arizona and Pennsylvania.

Why does it matter? Much of the care and support for people with IDD is provided by unpaid family members. Of the approximately 7.3 million people with IDD who live in the U.S., 80% live with a caregiver who is a family member (The Arc, 2018). Caregiving can result in added stress for the caregiver, loss of income, and reduced health and quality of life. During the pandemic, these stresses increased. According to the 2020-21 National Core Indicators COVID supplement to the AFS, 28% of respondents experienced loss of employment and 73% experienced changes, cancellations or reductions services. To respond to the challenges faced by caregiving families, 22 states sought amendments to their HCBS waiver Appendix K (emergency provisions) to expand their ability to pay family caregivers beyond the provisions of their current waivers. Paying families also expands the pool of support workers in light of the current workforce crisis.

Questions to ask: Paying family caregivers recognizes the key role they play in supporting their family member. However, the policy does raise some important issues. Does paying the family member constrain the ability of the participant to achieve independence? Are families aware of and trained in their obligations ensure people are included in the community, have opportunities for employment, and to make choices? Do payments to family caregivers cover the actual cost of support? Are there assurances that paying families is not a substitute for funding other paid supports? Is monitoring in place to ensure that individuals receive needed supports? In terms of equity, who has the means and opportunity to become a paid caregiver?

Want to know more?

The Arc (2018). "New Data Reveals Our Nation Is Failing to Support People With Intellectual and Developmental Disabilities." <https://tinyurl.com/yfrbprrx>

Friedman, C. and Rizzolo, M.C. (2016). Un/Paid Labor: Medicaid Home and Community Based Services Waivers that Pay Family as Personal Care Providers. *Intellectual and Developmental Disabilities*. Vol. 54 (4),233-244.

Williamson, H.J. & Perkins, E.A. (2014) "Family Caregivers of Adults with Intellectual and Developmental Disabilities: Outcomes Associated with U.S. Services and Supports," *Intellectual and Developmental Disabilities* 52, no. 2, 47-159, <https://tinyurl.com/5n8437r3>

*NCI-IDD Data in this Data Highlight come from the Adult Family Survey (AFS) which surveys families that live with an adult receiving services from their state developmental disabilities service systems. These data are intended to start a conversation on an important and growing issue that needs more attention, reflection, and understanding.