

ICI POLICY FORUM

INSTITUTE *on* COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA



MOST PEOPLE WITH IDD GETTING LONG-TERM SUPPORTS LIVE WITH A FAMILY MEMBER

Tuesday, November 1, 2022

Discussants: Sheryl Larson, ICI; Lynda Lahti Anderson, ICI; Nevil Genjang, UMN;
Sheli Reynolds, UMKC

Facilitator: Julie Bershadsky, ICI

POLICY RESEARCH BRIEF

MOST PEOPLE WITH IDD GETTING LONG-TERM SUPPORTS LIVE WITH A FAMILY MEMBER

Research Issue

Most people with IDD, whether they get funded supports or not, live with family members throughout their lives. Family caregivers are vital to people with IDD in living in their homes and supporting their full participation in their communities of choice. Public policies that focus scarce long-term services and supports (LTSS) resources on non-family settings at the expense of people living with family members fail to honor the critical role families play.

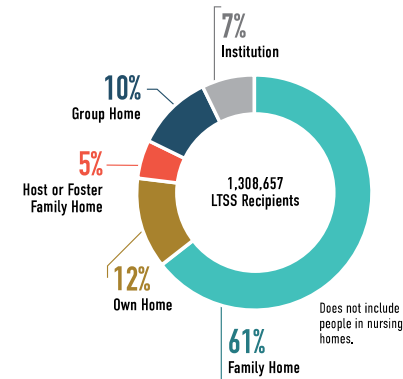
Medicaid Home- and Community-Based Services (HCBS) funding provides critical supports to people with IDD who live in their own home or with family members. It provides funds to purchase personal care, skill development training, family respite, employment support services, medical and behavioral support, transportation, environmental modifications, and many other essential supports. As a program jointly funded by federal and state dollars but operated by the states, there are many differences across states in how Medicaid funded long-term supports and services are arranged. Some states serve both adults and children through state IDD agencies while others house services for children in a different state agency. States use different eligibility criteria and offer different service menus. As a result, the proportion of service recipients with IDD who live with family members varies from state to state. This Policy Research Brief describes living arrangements for people with IDD, trends in Medicaid HCBS funding for people living with families, and state variations in the proportion of people with IDD living with families.

Study Background

The Residential Information Systems Project (RISP) at the University of Minnesota has tracked living arrangements for people with intellectual or developmental disabilities who receive Medicaid- or state-funded LTSS since 1977. Among other things, the project describes variations in service delivery patterns across states, changes in service delivery across time, changes in the types and sizes of residential settings in which people live, and the number of people who are eligible but waiting for Medicaid HCBS Waiver-funded supports. This Brief is based on data from a RISP report summarizing surveys of state IDD agencies for the year ending June 30, 2018.

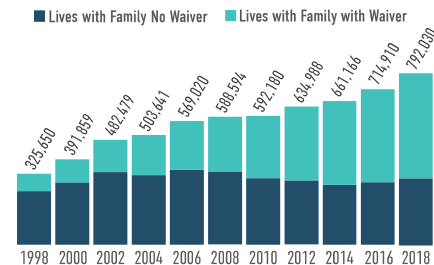
Key Findings

61% of LTSS recipients with IDD live with a family member in 2018.

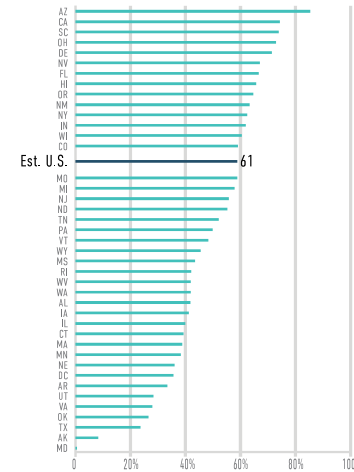


The number of people with IDD living with a family member who received LTSS more than doubled between 1998 and 2018.

The proportion of LTSS recipients living with a family member who received Medicaid Waiver-funded supports increased from 25% in 1998 to 61% in 2018.



The percent of LTSS recipients living with a family member varies by state. It ranged from 1% in Maryland to 88% in Arizona.



Join us **Tuesday, November 1st, 2022 from 1:00 to 2:30 p.m. CT on Zoom** for the Policy Forum on this issue of *Policy Research Brief*. [Register here](#).

The Policy Forum is a bi-monthly web-based presentation and facilitated discussion exploring research published in the most recent *Policy Research Brief*. Please visit the website, z.umn.edu/icpolicyforum, for details and to view previous forums.

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Larson, S. A., van der Salm, B., Pettingell, S., Sowers, M., & Anderson, L. L. (2021). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2018*. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018). *Family and individual needs for disability supports (v.2) community report 2017*. Minnesota: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

Policy Research Brief: z.umn.edu/rctprb

Family caregivers need improved access to high-quality, affordable supports.

Families supporting a child or adult with IDD report that caregiving requires them to periodically go into work late, leave early or take time off to provide care (91%), cut back their hours of work (55%), or give up work entirely (32%). Only 34% of family caregivers report being in excellent or very good health, and 94% were somewhat, very, or extremely stressed (Anderson, et al., 2018).

Policy Recommendations

Our policy recommendations include the following:

- The direct support workforce crisis affects all parts of the LTSS systems. Worker shortages have caused many families to go without services even when they have been authorized to receive Medicaid-funded supports. Policy efforts to address the workforce challenges through wage and benefit enhancements must be offered to all direct support workers including those who support families.
- Evaluation of the impact of the COVID-19 pandemic must consider its impact on families caring for members with IDD.
- Successful deinstitutionalization for people with IDD has been possible in part because of increased investments in publicly-funded supports for children and adults with IDD who live with family members. Those increased investments must continue. Public policy should also focus on reducing waiting lists for people with IDD living with family members.
- Increased funding is needed for supported competitive integrated employment and supports for meaningful day activities for people with IDD. This will help individuals with IDD to have better outcomes while also providing regular breaks from caregiving responsibilities for family caregivers.

Development of this PRB was supported by Cooperative Agreement #90DNPAD001-01 and Grant #90RT5019 from the Administration on Community Living to the University of Minnesota. Points of view do not necessarily represent official ACL policy.

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The University of Minnesota stands on *Miní Sdía Makhóche*, the rightful homelands of the *Dakhóta Oyáte*. We recognize the U.S. did not uphold its end of these land treaties. It is the current and continued displacement of the *Dakhóta Oyáte* that allows the University to remain today.

Ongoing oppression and discrimination in the United States has led to significant trauma for many people of color, immigrants, people with disabilities, and other oppressed persons. At ICI, we affirm our commitment to address systemic racism, ableism and all other inequalities and forms of oppression to ensure inclusive communities.

Research Issue

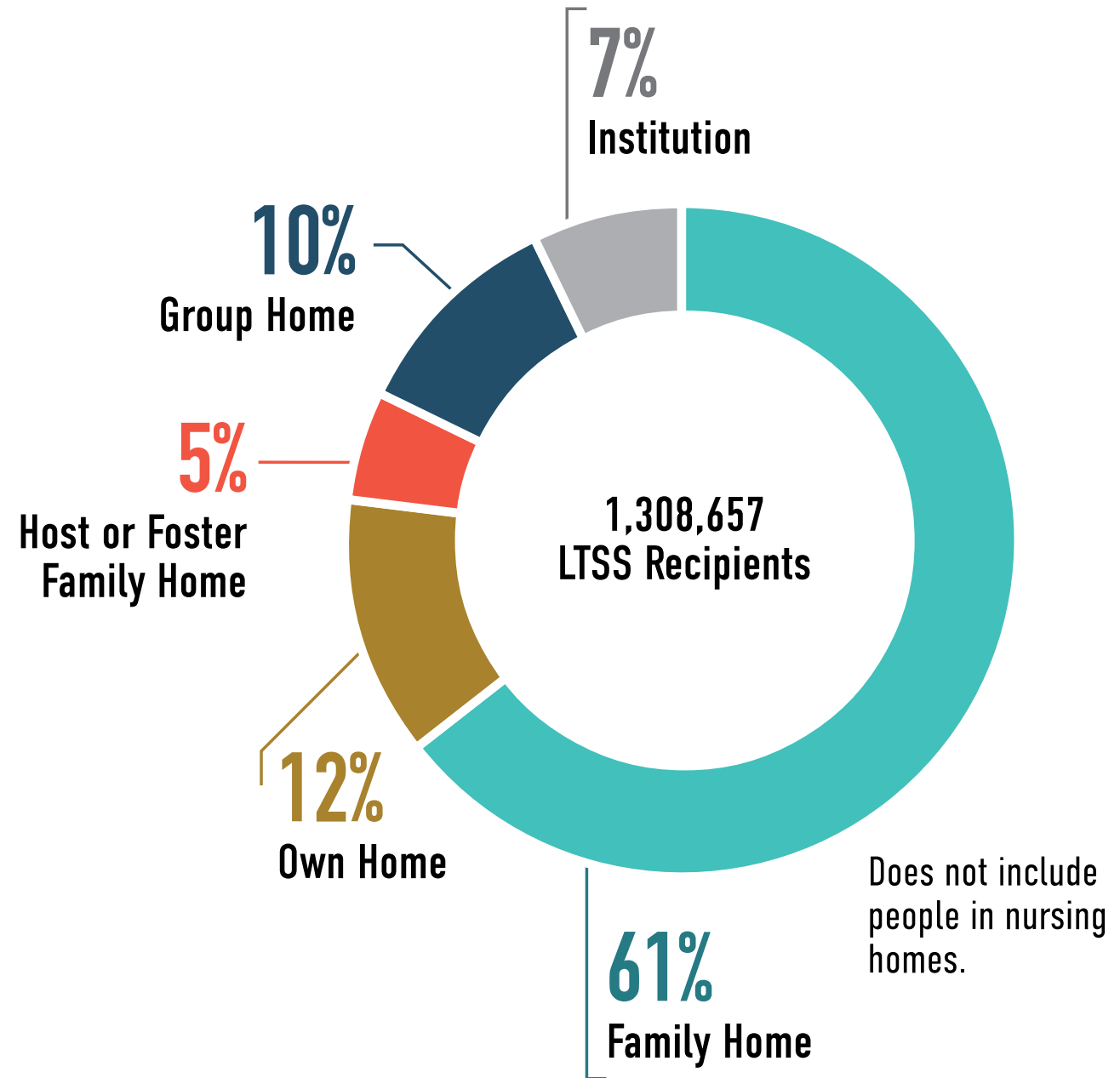
- Most people with IDD live with family members, who are vital in their lives.
- Public policies and LTSS resources must honor the critical role families play.
- The proportion of service recipients with IDD who live with family members varies from state to state.
- The Policy Research Brief describes living arrangements for people with IDD, trends in Medicaid HCBS funding for people living with families, and state variations in the proportion of people with IDD living with families.

Study Background

- The Residential Information Systems Project (RISP) studies the places people with IDD live when they get publicly-funded services.
- RISP is a **Longitudinal Data Project of National Significance** funded by the Administration on Community Living of the US Dept of Health and Human Services.
- The RISP project began in 1977 with a census of state-run IDD institutions.
- This presentation describes services as of June 30, 2018

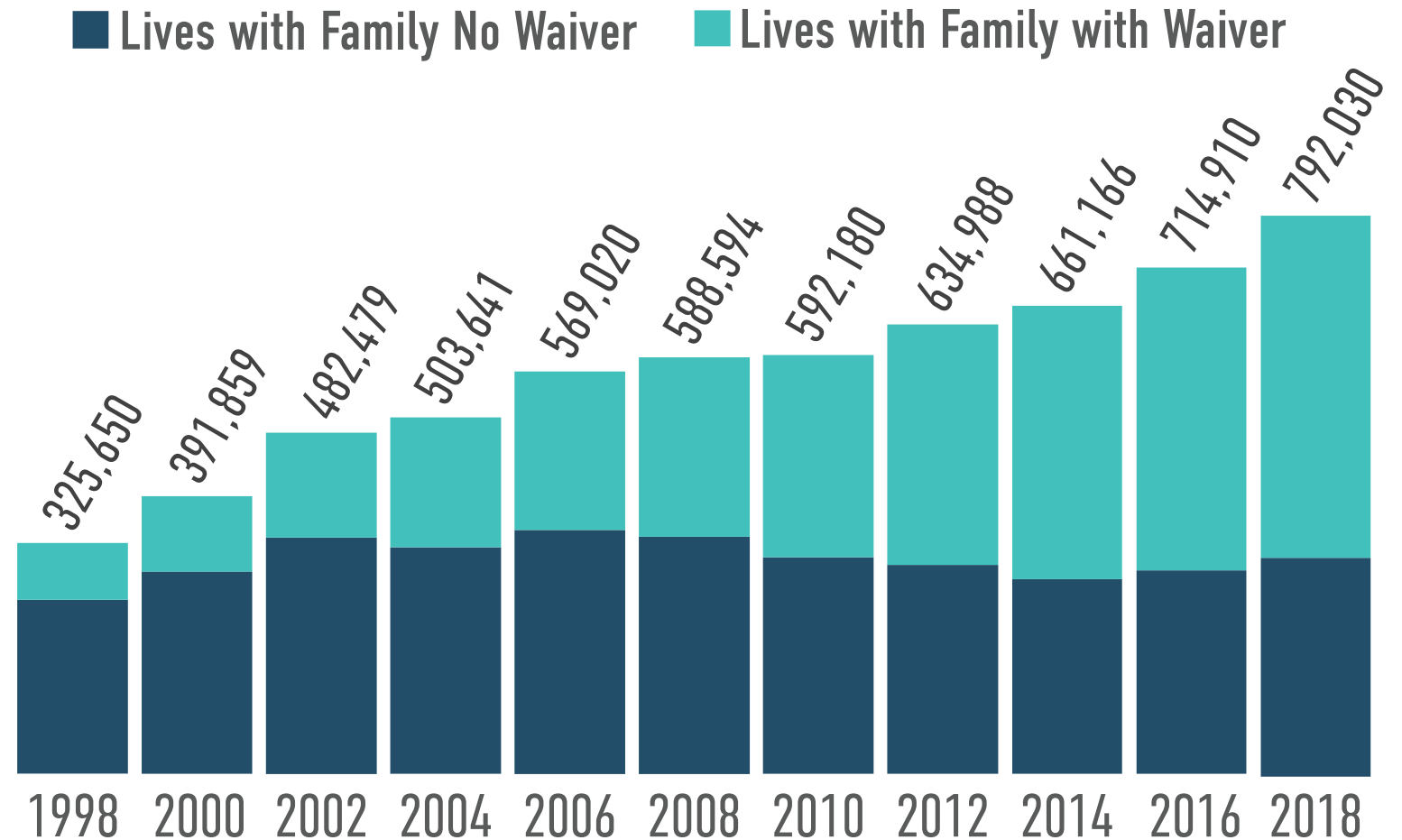
Key Findings

61% of LTSS recipients with IDD live with a family member in 2018

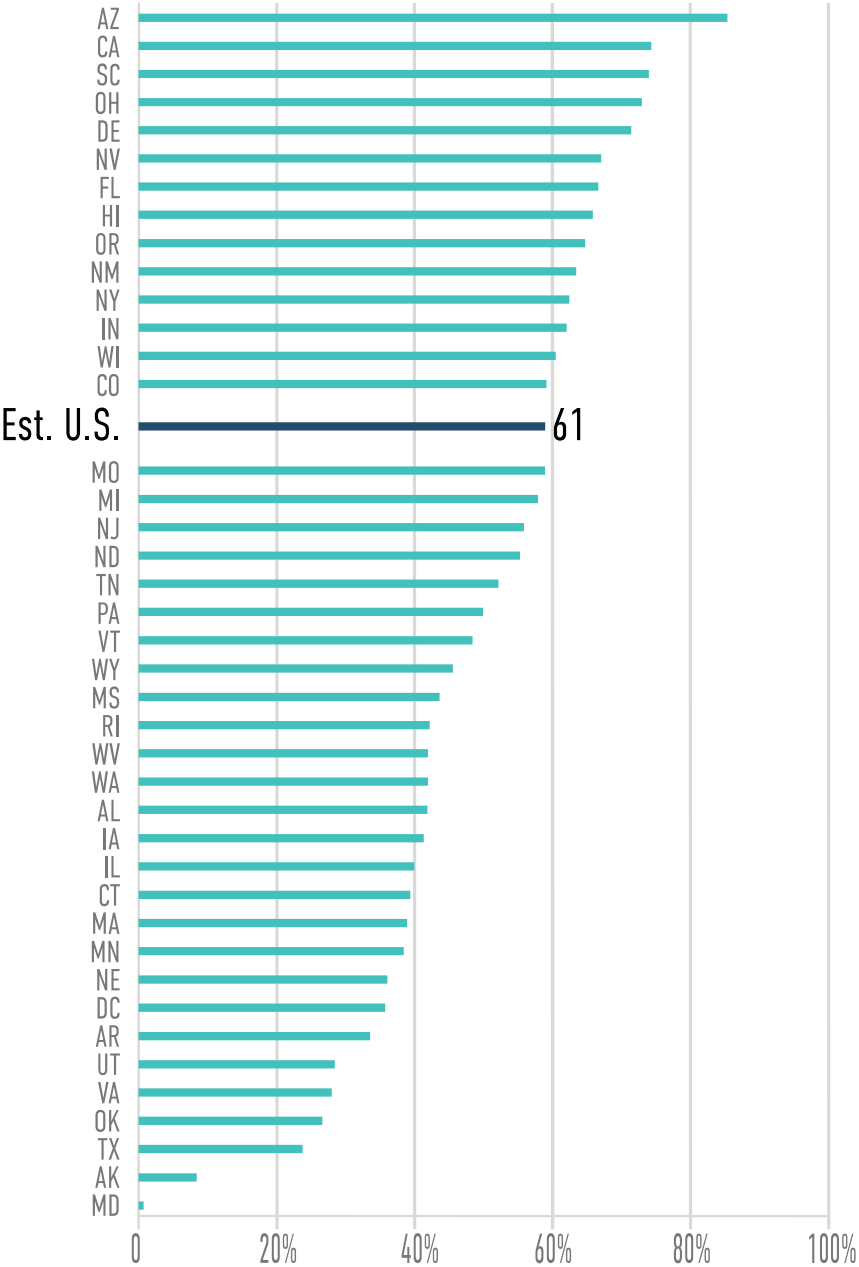


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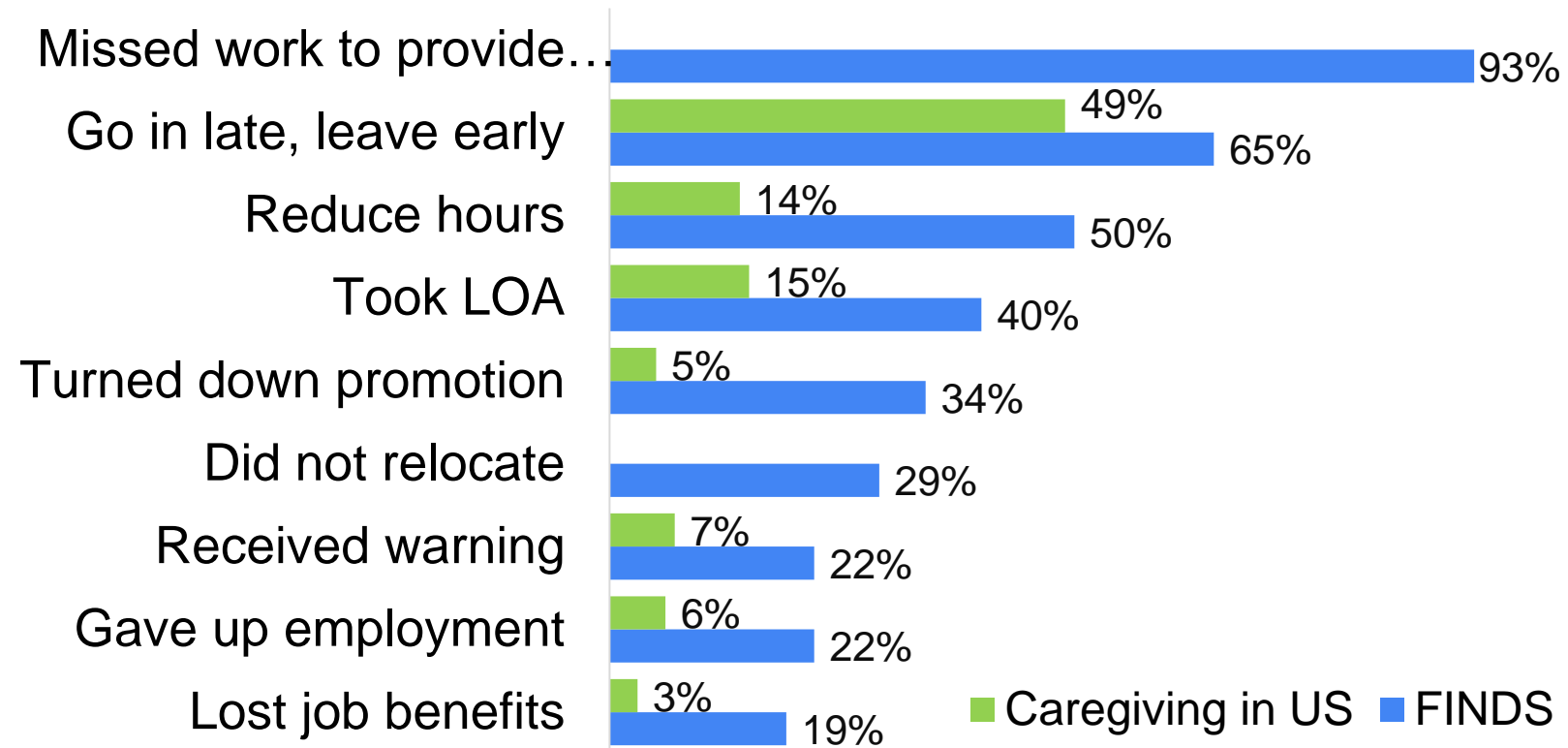
Family caregivers need improved access to high-quality, affordable supports.

Family caregivers experience:

- needing to go to work late
- having to leave early or take time off
- having to cut back on hours of work
- having to quit work entirely
- high stress levels
- health issues



FINDS data: Caregiving affects work



Policy Recommendations

- Policy efforts to address the workforce challenges through *wage and benefit enhancements* must be offered to all direct support workers *including those who support families*.
- Evaluation of the impact of the *COVID-19 pandemic* must consider its *impact on families caring for members with IDD*.
- Increased *investments* in publicly-funded-supports *for people who live with family members* must continue. Public policy should also focus on *reducing waiting lists for people with IDD living with family members*.
- *Increased funding* is needed for *supported competitive integrated employment and supports for meaningful day activities* for people with IDD.



Discussion Question

Is the growth of people living with family member (and receiving LTSS) a good thing?



Discussion Question

What are the implications of this growth?

For a copy of the slides and recording
go to the Institution on Community Integration's Policy Forum Page

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For a copy of the Policy Research Brief
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Thank you!

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The RISP project is funded through a cooperative agreement from the Administration on Community Living, U.S. Department of Health and Human Services Cooperative Agreement #90DNPA0001-01 with supplemental funding from the National Institutes on Disability, Independent Living and Rehabilitation Research Grant #90RT5019. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not therefore necessarily represent official ACL or NIDRR policy.

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In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2018



Residential Information Systems Project

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risp.umn.edu



for Individuals with Intellectual and/or Developmental Disabilities (1987-2017)



acl.gov/30years

Resources

- ICI, HSRI, & NASDDDS. (2022). *Community supports in crisis: No staff, no services*. Minneapolis, MN: University of Minnesota, Institute on Community Integration.
- Larson, S.A., & Lakin, K.C. (1991). Parent attitudes about residential placement before and after deinstitutionalization: A research synthesis. *Journal of the Association for Persons with Severe Handicaps*, 16, 25-38.
- Larson, S.A., Lakin, K.C., & Hill, S.L. (2012). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S. studies from 1977 to 2010. *Research and practice for persons with severe disabilities*, 37(4), 1-12.
- Larson, S.A., van der Salm, B., Pettingell, S., Sowers, M., & Anderson, L.L., (2021). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2018*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Ticha, R., Hewitt, A., Nord, D. & Larson, S.A. (2013). System and individual outcomes and their predictors in services and support for people with IDD. *Intellectual and Developmental Disabilities*, 51, 316-332.

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