

POLICY RESEARCH BRIEF

INSTITUTIONAL BIAS IN LONG-TERM SERVICES AND SUPPORTS FOR PEOPLE WITH IDD

INSTITUTE on COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA

Research Issue

The Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) program is Medicaid's institutional option for people with IDD who need long-term services and support (LTSS). The Medicaid Home and Community-Based Services (HCBS) Waiver option allows people to get services at home or in their preferred community setting rather than in an institution. The 2014 HCBS Settings Rule ensures that people receiving HCBS programs have full access to the benefits of community living and are able to receive services in the most integrated setting. While ICF/IID services are guaranteed, HCBS Waiver-funded services are not. States are not allowed to have waiting lists for ICF/IID services, but they can have waiting lists for HCBS Waiver-funded services. This results in an institutional bias in long-term supports and services for people with IDD.

Study Background

The Residential Information Systems Project (RISP.umn.edu) at the University of Minnesota has tracked the size and type of living arrangements for people with IDD who get Medicaid or state-funded LTSS since 1977. This brief is based on Fiscal Year 2019 RISP survey results. It also cites findings from the National Core Indicators In-Person Survey.

POLICY FORUM



This Policy Forum for this issue of Policy Research Brief will be **Tuesday, October 3rd, 2023 at 1:00 p.m. Central on Zoom.** [Register here.](#)

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

Key Findings

It costs more to support a person in an institution than in the community.

In 2019, average annual per person spending was \$140,210 for people in ICF/IID settings compared with \$48,458 for HCBS Waiver recipients.

\$140,210



\$48,458



ICF/IID (Institution) HCBS Waiver (Community)

People in smaller community settings have more choice.

Research using the National Core Indicators In-Person Survey shows that people living in smaller community settings have more choices in what time they eat and go to bed, what they do with their free time and how they spend their money. They also have more say in who supports them and where they live and work.



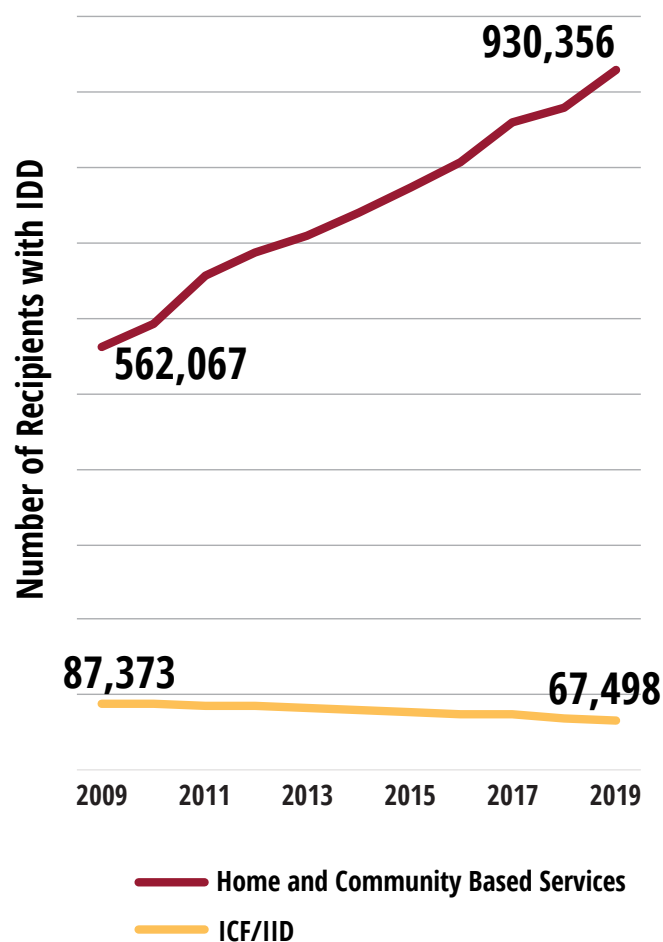
**Small settings
More choice**



**Big settings
Less choice**

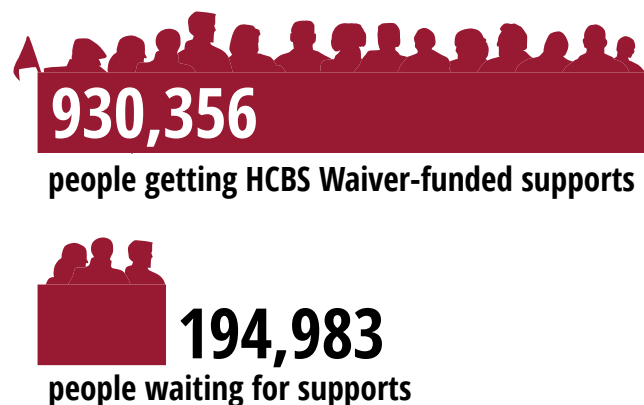
The number of HCBS Waiver recipients grows every year while the number ICF/IID recipients continues to decline.

In 2019, there were 930,356 HCBS Waiver recipients compared to 67,498 people in ICF/IIDs.



Many states have long waiting lists for HCBS Waiver-funded services.

In 2019, 194,983 people living in their own homes or with a family member in 30 states were waiting for HCBS Waiver-funded supports.



Policy Recommendations

- Continue to reduce use of expensive ICF/IID settings.
- Eliminate Medicaid's institutional bias by making HCBS an entitlement.
- Continue to promote the use of HCBS that support person-centered services, full community inclusion and individual choice.
- Enforce all provisions of the 2014 Medicaid HCBS Rule to promote person-centered services, full community inclusion and individual choice.

Published, September 2023.

Editors: Agnes Cole, Brian Begin, and Sheryl Larson

Graphic design: Connie Burkhart

Larson, S.A., Neidorf, J., Pettingell, S., Sowers, M. (2022). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2019*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. DOI: 10.13140/RG.2.2.23116.08320.

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.

Policy Research Brief: z.umn.edu/rtcprb

This project is funded through a cooperative agreement from the Administration on Community Living, U.S. Department of Health and Human Services, Cooperative Agreement #90DNPA0001-05 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 freely express their findings and conclusions. Points of view or opinions do not therefore necessarily represent official ACL or NIDILRR policy.

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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.