POLICY RESEARCH BRIEF

DECLINING USE OF RESIDENTIAL SETTINGS OF SEVEN OR MORE PEOPLE WITH IDD

INSTITUTE on COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA

Research Issue

The number of people with intellectual or developmental disabilities (IDD) living in institutions has been declining for decades. However, many people with IDD still live in settings with 7 or more people.

People living in small settings live better lives than those living in institutions. For example, people living in small settings can make more choices about their lives. They are also less likely to get viruses such as COVID-19 and other spreadable diseases (e.g., Levinson, et al., 2024; Ticha et al, 2013).

The Centers for Disease Control and Prevention (CDC) Healthy People 2030 goal DH-03 is to reduce the proportion of people with IDD living in facilities with seven or more people to 11.5% by 2030.

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 the Fiscal Year 2020 RISP survey results.

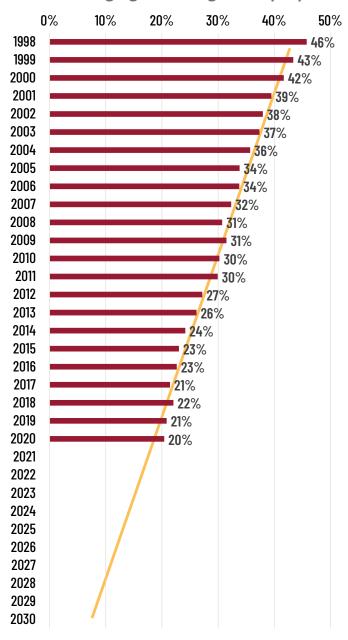
Key Findings

Many people still live in large settings.

In 2020, among people with IDD getting long-term supports who didn't live with a family member, 113,819 (20%) lived in settings of 7 or more people. Of them, 49,533 (9% of all people with IDD in non-family homes) lived in IDD-specific group settings of seven to 15 people, 36,283 (6%) lived in IDD group settings of 16 or more, 25,749 (5%) lived in nursing homes, and 2,254 (0.4%) lived in psychiatric facilities.

The proportion of people with IDD living in nonfamily settings housing seven or more people is declining steadily.

Percent of people in non-family settings who live in congregate settings of 7 + people



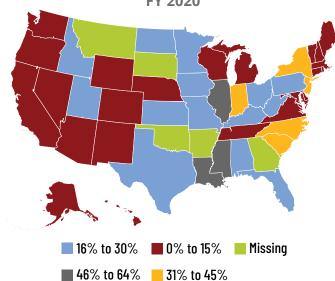
Linear (% in settings of 7+)

% in settings of 7+

In 1998, 46% of people with IDD getting long-term supports who didn't live with a family member lived in settings of 7 or more people. In 2020, that percentage was down to 20%. If the trend continues to decline at the same rate, the CDC goal will be achieved by 2028.

There are big differences across states in the use of large group facilities.

Percent of long-term supports recipients not living with a family member who lived in a facility housing seven or more people in FY 2020



States in which more than 50% of people with IDD in residential settings live in places with 7 or more people are Illinois, Louisiana, and Mississippi. States in which 5% or fewer people in residential settings live in places with 7 or more people include Colorado, the District of Columbia, Hawaii, New Hampshire, Oregon, Vermont, and Wisconsin.

States differ for many reasons, including state Medicaid policy, state wealth, and previous efforts downsizing or closing large facilities.

While some IDD facilities of 7 or more people are licensed and regulated as institutions, many are not.

Of the 85,262 people in IDD group settings of seven or more people, 45,618 were in Medicaid institutions licensed as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). The remaining 39,644 people received services funded by Medicaid Home and Community-Based Services (HCBS) or by state or local funds.

HCBS has rules that emphasize that people are integrated in their communities, while ICF/IDD regulations focus more on physical space and do not have similar rules.

Policy Recommendations

- Downsize or close IDD facilities serving 7 or more people.
- Limit the use of nursing homes and psychiatric facilities to house people with IDD.
- Ensure provider-operated HCBS residential settings of all sizes comply with all of the 2014 Medicaid HCBS Rule settings provisions.
- States still housing people with IDD in settings of seven or more people should consult with states that have closed most or all such facilities to identify ways to reduce the use of large facilities.



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, <u>z.umn.edu/icipolicyforum</u>, for details and to view previous forums.

Published, December 2024

Guest editors: Jackson DuFauchard, Sherri Larson, Jon Neidorf, and Brian Begin Editor-in-chief: Julie Bershadshky Graphic design: Connie Burkhart

The University of Minnesota is an equal opportunity educator and employer. This document is available in alternative formats upon request.

Research cited

Larson, S.A., Neidorf, J., Begin, B.C., Pettingell, S., Sowers, M. (2024). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2020.* Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Levison JH, Fung V, et al., (2024). Predictors of COVID-19 Infection and Hospitalization in Group Homes for Individuals with Intellectual and/or Developmental Disabilities, *Disability and Health Journal*, https://doi.org/10.1016/j.dhjo.2024.101645.

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* (5), 298-315

Policy Research Brief: z.umn.edu/rtcprb

Development of this PRB was supported by Cooperative Agreement #90DNPA0001-01 and Grant #90RT5019 from the Administration on Community Living to the University of Minnesota. Points of view do not necessarily represent official ACL policy.

The University of Minnesota stands on Miní Sóta Makhóčhe, 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.