

POLICY RESEARCH BRIEF

ARE LARGE INSTITUTIONS FOR PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES A THING OF THE PAST?

Research Issue

Before 1967, state-run IDD institutions were the first and often only option for people with intellectual or developmental disabilities (IDD) to get an education or training. Doctors often urged families to put infants and children with IDD into an institution and forget about them. Institutions provided basic care. But they were miserable places to live.

Deinstitutionalization is the process of reducing the number of people living in large institutions by helping people move to or remain in their own homes or other small community settings. Reducing the number of people living in institutions and helping people with IDD get the help they need in community settings has been a priority for people with disabilities, their families, disability advocates, and Federal and State agencies for decades. For example, in Healthy People 2030, a Centers for Disease Control and Prevention (CDC) goal was to reduce the proportion of people with IDD who live in group settings of seven or more people from 22.7% in 2016 to 11.5% by 2030.

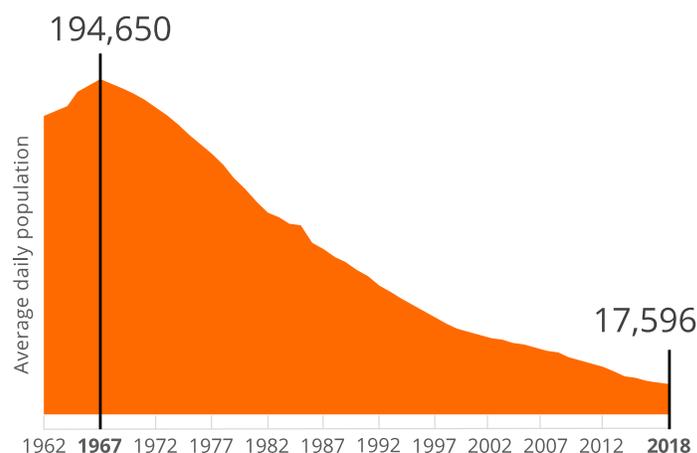
Seventeen states have already closed all large state-run IDD institutions. If the trends from 1992 to 2018 continue, the remaining state-run IDD institutions could close as soon as 2025. However, it is too soon to tell how the COVID-19 pandemic could affect those trends. This brief examines deinstitutionalization trends and policy recommendations.

Study Background

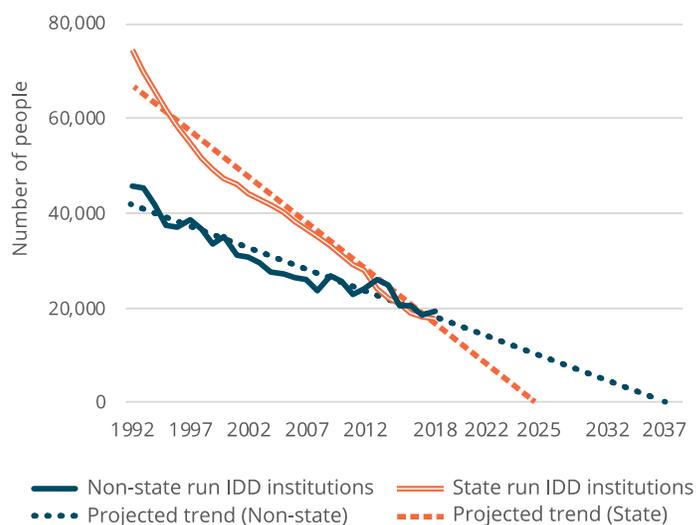
The Residential Information Systems Project (RISP) at the University of Minnesota has been tracking living arrangements for people with IDD who get Medicaid or state-funded long-term supports and services since 1977. The annual RISP survey of state IDD agencies asks about types and sizes of the places people with IDD getting supports live. This brief is based on survey results published in 2021, and covering services through period ending June 30, 2018.

Key Findings

Fifty years ago there were 10 times more people living in large state-run institutions than there are today.



If trends from 1992 to 2018 continue, all large state run IDD facilities could close or serve fewer than 15 people by 2025.

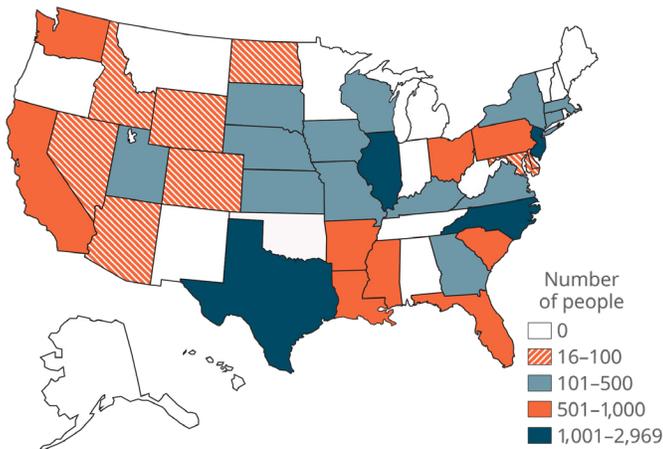


Until 2017, most people in large IDD institutions lived in state-run facilities. Now, most live in facilities run by non-state organizations.

In 2018, there were 17,557 individuals with IDD living in large state-run facilities and 19,268 living in facilities run by non-state organizations.

States continue to reduce the number of people with IDD living in state-run facilities of 16 or more people.

By 2018, 17 states closed all large state-run institutions for people with intellectual or developmental disabilities. However, 17,557 people still lived in 115 large state-run institutions in 34 states. The number of people living in large state-run IDD institutions was less than 100 in 8 states, between 100 and 1,000 in 22 states, and more than 1,000 in 4 states.



Policy Recommendations

Our policy recommendations include the following:

- Workforce shortages made more severe by the COVID-19 pandemic threaten access to home and community-based supports for people with IDD. Policy makers must address those shortages to ensure that people with IDD can move to or remain in their own homes and other community settings while getting needed supports.
- As the remaining large state-run IDD facilities close, the focus of deinstitutionalization efforts will shift to facilities operated by non-state providers. Different policy levers may be needed to incentivize non-state providers to downsize or close facilities for seven or more people.
- States should use Medicaid rebalancing and other incentives to downsize and close all IDD facilities serving 16 or more people. They should instead provide home and community-based support to people in individualized settings such as the person's own home, the home of a family member, or a host or foster family home.
- The seventeen states that have already closed all large state-run IDD facilities have found ways to support all people with IDD, regardless of age or type or intensity of support needs in home and community-based settings. Policy initiatives and technical assistance efforts should help the remaining states to do the same.

POLICY FORUM



Join us **June 23rd, 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/icipolicyforum, for details and to view previous forums.

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Policy Research Brief: z.umn.edu/rtcprb

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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.