

The State of the States in Intellectual and Developmental Disabilities

Data Brief 2018 (2)



Rebalancing of Long-Term Supports and Services for Individuals with Intellectual and Developmental Disabilities in the United States

Amie Lulinski, PhD, Nicole T. Jorwic, JD, Emily Shea Tanis, PhD, & David Braddock, PhD

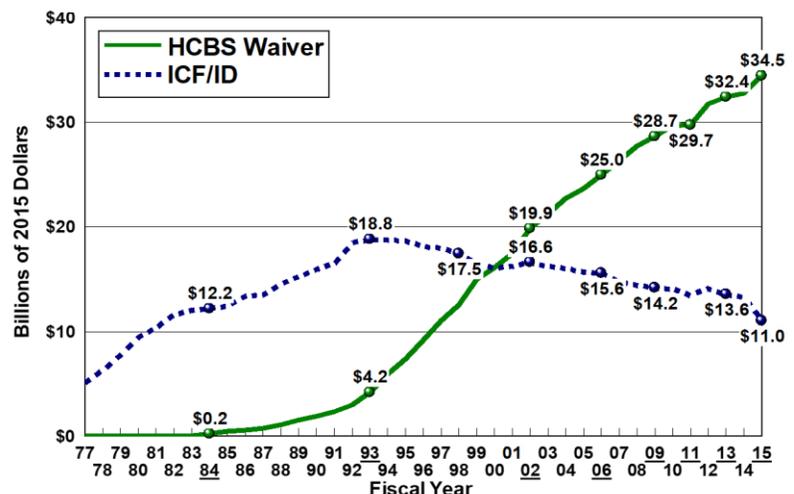
Background

In 1965, Medicaid was created to finance health care for the aging population, people with disabilities, and the poor. A federal/state partnership in which costs are shared between the federal government and states, the federal government matches state financial investments in Medicaid services based on a formula called Federal Medical Assistance Percentages (FMAP), which takes into account state wealth. All 50 states and the District of Columbia have a Medicaid program.¹

While Medicaid is a federally administered program, states retain authority and flexibility in providing services to targeted populations on condition that they meet basic Medicaid requirements. Medicaid funds both mandatory services, which states are required to provide under federal law, and optional services that states may opt to cover. Mandatory services include skilled nursing facilities, x-rays, and physician services. Optional services include dental services, transportation, and home and community-based waiver services (HCBS), such as personal care attendants, speech therapy, employment supports, and other services that allow individuals to live in the community.

HCBS is funded through the Medicaid waiver program that waives certain provisions of the Social Security Act to allow for the provision of services outside of institutional settings. The HCBS program waiver began in 1981 as a means to correct the “institutional bias” of Medicaid funding by offering an alternative to institutional services. The vast majority (76%) of the supports and services that individuals with I/DD use to

Figure 1. Public Spending on IDD Services 1977 - 2015



¹ The US territories of American Samoa, the Commonwealth of the Northern Marianas Islands, Guam, Puerto Rico, and the US Virgin Islands have a Medicaid program but they do not receive an FMAP. For more information see: <https://www.acl.gov/sites/default/files/programs/2017-03/Combined-Territories.pdf>.

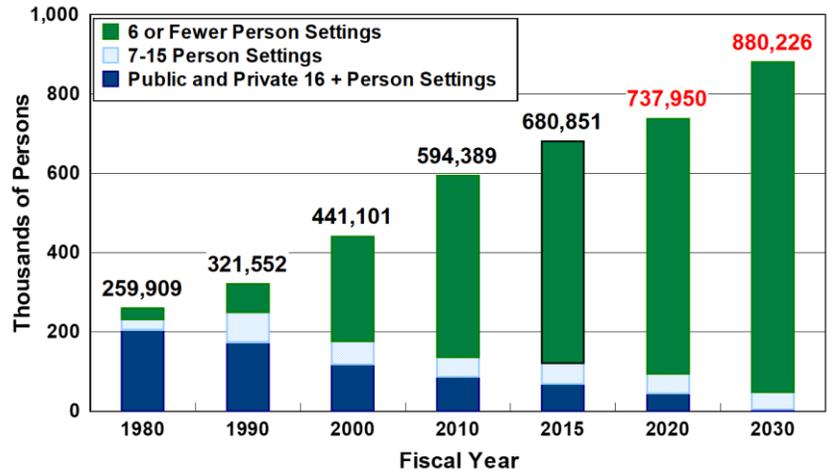


live in the community are funded through the Medicaid program. In fact, HCBS waiver expenditures surpassed institutional spending in 2000 and continued to rise while institutional spending has decreased as illustrated in Figure 1 (Braddock, Hemp, Tanis, Wu, & Haffer, 2017).

In 1967, the nation's IDD institutional census peaked at 194,650. By the end of fiscal year 2015, that number had fallen to 21,103, a decrease of 89%. If institutional numbers continue to decline along this trend, the nation's institutional census will reach zero by 2030 (Figure 2).

Also illustrated in Figure 2, is the increase of people living in smaller settings. In FY2015, 559,172 people (82%) who lived outside of their family home resided in settings for six or fewer.

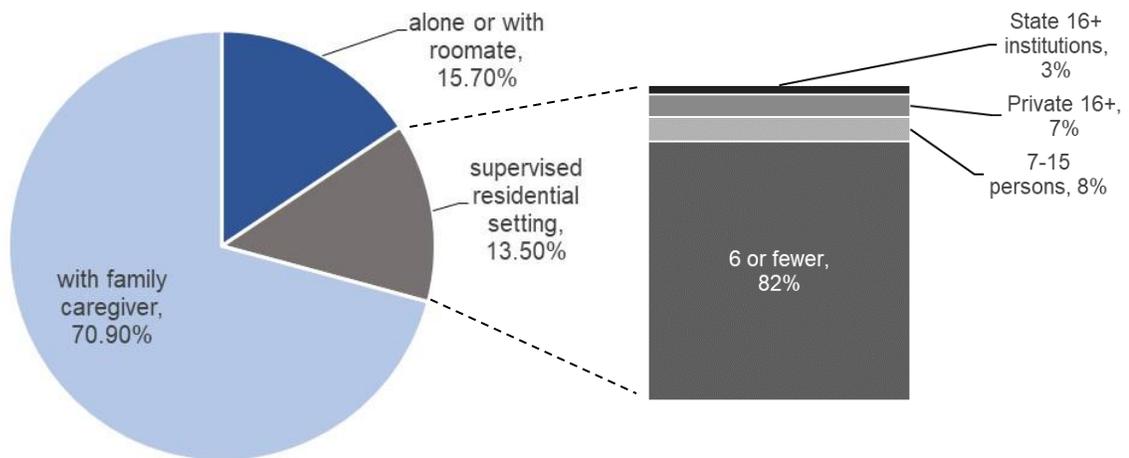
Figure 2. Number of people living in settings by size (1980 – 2030*)



*2020 and 2030 are estimates

Families are the predominant provider of residential supports for people with IDD in the United States. As shown in Figure 3, in FY2015, nearly 71% of people with IDD lived with a family caregiver while 15.7% lived alone or with a roommate, and 13.5% lived in a supervised residential setting.

Figure 3. Estimated Distribution of People with IDD by Living Arrangement (FY 2015)



In FY2015, the average institutional cost per person was \$210,110 while the average waiver cost per person was \$46,481.

Rebalancing

Rebalancing of long-term supports and services (LTSS) is a broad effort by states and the federal government to provide supports and services to seniors and people with disabilities in appropriate, permanent, integrated community-based settings instead of more costly congregate institutional settings. In FY2015, the average institutional cost per person was \$210,110 while the average waiver cost per person was \$46,481. For the average cost to provide residential supports to one person in an institution, 4.5 people could receive HCBS waiver supports. Rebalancing continues to be a focus of federal and state governments, but additional investments and changes to the Medicaid law to remove existing institutional bias would allow investments in community services to grow.

Waiting Lists

While waivers offer states a lot of flexibility, they also permit states to limit services by restricting benefits to specific groups (for example, children with autism) and to cap enrollments (for example, 200 adults). These restrictions significantly contribute to the long wait lists for many waiver services in states throughout the country. In FY 2015, there were 428,151 people on waiting lists for 1915(c) waiver services (The Kaiser Family Foundation, 2018).

Focus on Rebalancing Must Remain

States have made great strides in rebalancing the system to the community, but supports must continue. Programs like Money Follows the Person (MFP) provide additional funding which allows states to transition individuals from institutional settings into community-based settings as well as make necessary systemic changes. As of December 2013, 7,487 individuals with IDD transitioned from institutional to community placements at a cost savings of \$361 million. Without MFP, 50% participants with IDD would not have transitioned into the community (Irvin, Bohl, Stewart, Williams, Steiner, Denny-Brown, Wysocki, Coughlin, Smoot & Peebles, 2017). Funding authorization for MFP expired in September of 2016. Presently, bipartisan bills to reauthorize this program have been introduced both the House (H.R. 5306) and the Senate (S.B. 2227). We rely upon the strong advocacy of the disability community to support programs like MFP in addressing the long-term supports and services needs for people with intellectual and developmental disabilities and their families.



References

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Author affiliations

Amie Lulinski, PhD, Coleman Institute for Cognitive Disabilities, University of Colorado

Nicole T. Jorwic, JD, The Arc of the United States

Emily Shea Tanis, PhD, Coleman Institute for Cognitive Disabilities, University of Colorado

David Braddock, PhD, Coleman Institute for Cognitive Disabilities, University of Colorado

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The State of the States in Intellectual and Developmental Disabilities Project is a national longitudinal comparative study of financial and programmatic trends in spending on supports and services for people with IDD in the United States. It is a Data Project of National Significance and receives funding from the Administration on Community Living. For additional information visit www.stateofthestates.org or email us at stateofthestates@cu.edu.



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