Public Support for People with Intellectual and Developmental Disabilities

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Nearly 9.5 million children and adults with intellectual and developmental disabilities (IDD) receive government financial payments for long-term care (0.9 million), health care (3.5 million), income maintenance (3.8 million) and special education (1.3 million). Until the 1980s, public and private institutions and large group residences were the dominant state-financed settings providing services for this population. However, efforts in the states to provide long-term services and supports (LTSS) in community settings have grown. States have shifted investments from segregated public and private institutions to small community-based settings and family homes.

Individual and family support (IFS) includes public funding for adults with IDD in neighborhood homes and apartments, as well as support for children and adults living in their families’ homes.

Table 1

<table>
<thead>
<tr>
<th>Type of support</th>
<th>% change 1995-2015</th>
<th>Average Cost in 2015</th>
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<tbody>
<tr>
<td>IFS Spending</td>
<td>540%</td>
<td>$16,518</td>
</tr>
<tr>
<td>7+ residences</td>
<td>-45%</td>
<td>$73,384</td>
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The average per-person cost for group homes serving seven or more residents in FY 2015 was $73,384, compared to $16,518 per person for individual and family support (Table 1). During fiscal years 1995 to 2015, inflation-adjusted spending for IFS grew 540 percent, while spending for larger group residences (those housing seven or more people) dropped 45 percent. The cost of individual and family support in fiscal year 2015 was only 23 percent the cost of care for people with intellectual and developmental disabilities living in the larger public and private group residences and institutions.

The number of people living in residences with seven or more people fell as well. Between FY 1995 and FY 2015, that number dropped by 46 percent while those receiving individual and family support participants increased 168 percent. In 2015, the number of IFS participants and families was more than seven times the number of people living in residences with seven or more people (970,718 compared with 133,665).

More than 4 million children and adults with intellectual and developmental disabilities live in the family home. However, Figure 1 illustrates that a comparatively small proportion, 15 percent, were receiving state IDD agency financial support in 2015.

Federal Action

State Medicaid programs are required by the federal government to provide nursing home services, while home- and community-based services (HCBS) are optional. An HCBS waiver was authorized in 1981 when Congress and the Reagan administration agreed on a plan to reduce Medicaid spending by offering an alternative to institutional services. Since FY 1981, states have used additional Medicaid waiver options to support individuals with intellectual and developmental disabilities and their families in their home communities. Waiver options now include Money Follows the Person, the Balancing Incentive Payment Program (BIPP) and Community First Choice (CFC). In addition, optional state plan services—including personal care, home health care, targeted case management, clinic services and rehabilitative services—are also available in the states. Collectively, these services are termed Community Medicaid Long-Term Services and Supports programs. Total HCBS expenditures surpassed institutional Medicaid expenditures in
Institutional Medicaid spending has been decreasing significantly in the states.

State Action
States now use the wide range of community-based Medicaid services to finance community options for people with intellectual and developmental disabilities and their families. During FY 1995 to FY 2015, Community Medicaid LTSS increased from 18 percent to 65 percent of the total IDD LTSS spending, which was $65.2 billion in 2015.

The increased Medicaid spending for community-based options and individual and family support is a major factor in reducing the cost of care per recipient compared to public and private institutions and group residences. In addition, community-based Medicaid options provide the flexibility for people with intellectual disabilities to remain in their family home and to interact with others in their home communities.

Even with the progress states have achieved in rebalancing their systems of care for people with intellectual and developmental disabilities, challenges remain. An estimated 4.1 million people with IDD were living with a family caregiver in 2015 and 24 percent of their caregivers are over the age of 60. In 2015, 741,285 people with IDD received HCBS services in the United States while 428,151 remained on a waiting list for services. State policymakers continue to seek innovative solutions in their oversight of the federal-state Medicaid program to meet the needs of people with intellectual and developmental disabilities in the most effective and efficient ways possible.

References
2. Kaiser Family Foundation (2017). Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers.