Medicaid and the Disabled in Illinois: Policy Challenges of Long-Term Care

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In 1999, the U.S. Supreme Court issued a landmark decision in *Olmstead v. L.C.*, which held that unjustified institutionalization of people with disabilities could be regarded as discrimination under the Americans with Disabilities Act of 1990 (ADA). The plaintiffs in the case were two Georgia women with disabilities that included both mental retardation and mental illness. The Court’s opinion declared that states were not required to make “fundamental alterations” in their services and programs as a remedy for discrimination, but that they did have to make “reasonable modifications” to assure accessibility to community-based services. A state could meet its obligations under ADA by having a “comprehensive, effectively working plan” for placing qualified individuals with disabilities in less restrictive, community-based settings (see Rosenbaum and Teitelbaum, 2004).

Although the *Olmstead* case was not about Medicaid per se, the Court’s decision does have substantial implications for the Medicaid program, which is the nation’s single largest source of funding for long-term care. The policy challenges presented by *Olmstead* are especially critical for Medicaid in Illinois, where the disabled represent a relatively high proportion of spending for institutional long-term care and where the movement to community-based services has been relatively slow and uneven.

The Disabled Share of Medicaid Spending

In Illinois, the disabled eligibility group accounts for less than one-fifth of Medicaid enrollment but more than half of total spending. One complicating factor is that a substantial number of the state’s seniors are enrolled in the disabled rather than the aged eligibility group. This group of seniors consists of individuals who entered the Medicaid program as disabled before reaching age 65. In federal fiscal year (FFY) 2001, Illinois spent 51 percent of its Medicaid dollars on disabled recipients, compared with 45 percent nationwide. If disabled seniors are excluded, however, the disabled share of total Medicaid spending in Illinois drops to 44 percent, which is close to the U.S. average (see Exhibit 1).
Institutional Long-Term Care

Medicaid spending for institutional long-term care encompasses both nursing home services for the elderly and the disabled and intermediate care facilities for persons with developmental disabilities (ICF-DDs). In FFY 2001, disabled recipients accounted for 57 percent of institutional long-term care spending in Illinois, which was much higher than the U.S. average (36%) and highest among midwestern states. The share for non-elderly disabled recipients in Illinois was 46 percent, a figure that was closer to the nationwide average (about 32%) but still highest in the Midwest (see Exhibit 2).

Exhibit 1: Medicaid Enrollment and Spending by Eligibility Group, FFY 2001

<table>
<thead>
<tr>
<th>Illinois</th>
<th>U.S. total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Enrollment</td>
</tr>
<tr>
<td>Disabled</td>
<td>15.7%</td>
</tr>
<tr>
<td>Under age 65 (est.)</td>
<td>13.5%</td>
</tr>
<tr>
<td>Age 65 and over (est.)</td>
<td>2.2%</td>
</tr>
<tr>
<td>Aged</td>
<td>6.3%</td>
</tr>
<tr>
<td>Children in low-income families</td>
<td>53.0%</td>
</tr>
<tr>
<td>Adults in low-income families</td>
<td>20.5%</td>
</tr>
<tr>
<td>Foster care/adoptive assistance</td>
<td>4.6%</td>
</tr>
</tbody>
</table>

Note: Totals exclude data for “basis of eligibility unknown.”
Source: Centers for Medicare and Medicaid Services, Medicaid Statistical Information System.

Exhibit 2: Disabled Share of Medicaid Spending for Institutional Long-Term Care, FFY 2001

Note: Totals exclude spending for "basis of eligibility unknown." U.S. figure is an estimate.
Source: Centers for Medicare and Medicaid Services, Medicaid Statistical Information System.
Medicaid-funded nursing home services in Illinois are administered through the Department of Public Aid’s Bureau of Long Term Care. Although most nursing home residents have physical impairments, some nursing facilities also include individuals with developmental disabilities or mental illnesses. In FFY 2001, the disabled accounted for about 35 percent of Medicaid spending for nursing home care in Illinois, compared with only 20 percent nationwide. Excluding disabled seniors, the disabled share was about 20 percent in Illinois and 15 percent in the U.S. as a whole.

The Illinois Department of Human Services is responsible for long-term care and other services for persons with developmental disabilities. One of the most distinctive features of long-term care in Illinois is the prominent use of ICF-DDs, especially larger facilities with 16 or more beds (Gettings, Cooper, and Chmura, 2003; Rizzolo et al., 2004). In FFY 2003, public and private ICF-DDs represented more than 30 percent of all Medicaid spending for institutional long-term care in the state, compared with about 20 percent nationwide. The proportion of spending for ICF-DDs in Illinois was also 5th highest among all states (see Exhibit 3).

### Exhibit 3: Medicaid Spending for Institutional Long-Term Care, FFY 2003

<table>
<thead>
<tr>
<th>Service Description</th>
<th>Illinois</th>
<th>U.S. total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing facilities</td>
<td>68.1%</td>
<td>79.9%</td>
</tr>
<tr>
<td>Intermediate care facilities for the developmentally disabled</td>
<td>31.9%</td>
<td>20.1%</td>
</tr>
<tr>
<td>Public</td>
<td>14.6%</td>
<td>12.2%</td>
</tr>
<tr>
<td>Private</td>
<td>17.3%</td>
<td>8.0%</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Source: Medstat Group, Inc., based on data from the Centers for Medicare and Medicaid Services, CMS-64 reports.

**Community-Based Long-Term Care**

Medicaid funding for non-institutional long-term care falls into three main areas: home health services (a mandatory Medicaid benefit), personal care services (an optional benefit), and Home and Community-Based Services (HCBS) waiver programs. In most states, including Illinois, the largest of these spending categories is HCBS waiver programs, which provide alternative forms of service delivery for individuals who would otherwise be at risk of placement in institutional care. The waivers allow states to offer a wide range of services that would normally not be covered by Medicaid, as well as to restrict services to certain geographic areas and limit the number of individuals who can participate in the program.

Illinois currently has seven HCBS waivers, with disabled recipients accounting for about 85 percent of all expenditures. The state’s largest waiver in terms of spending is a program for adults with developmental disabilities. Nationwide, persons with developmental disabilities represent about 40 percent of HCBS waiver participants and 75 percent of waiver spending (Reester, Missmar, and Tumlinson, 2004). Total HCBS waiver expenditures in Illinois have more than doubled since FFY 1997. Compared with other states, however, Illinois still relies heavily on institutional long-term care services. In FFY 2003, HCBS waivers and other community-based services represented 20 percent of Illinois’s Medicaid spending for long-term care (see Exhibit 4). This figure was well below the nationwide average (33%) and lower than all but six states.
Illinois’s Response to Olmstead

In January 2000, the U.S. Department of Health and Human Services (HHS) sent the first of a series of letters to all state Medicaid directors regarding the *Olmstead* decision. States were urged to increase access to community-based services for the disabled by developing comprehensive working plans for compliance with ADA. HHS also reminded states of their responsibilities under Medicaid “to periodically review the services of all residents in Medicaid-funded institutional settings” (Westmoreland and Perez, 2000). By the end of 2003, *Olmstead*-related plans or reports had been issued in 29 states. Actual implementation of state plans has been limited, however, partly because of severe fiscal pressures (Fox-Grage, Coleman, and Folkemer, 2004).

In April 2002, Illinois released a *Community Living and Disabilities Plan* that established a “framework” for achieving “greater integration of persons with disabilities into community life” (IDHS, 2002). The plan was developed with input from more than 200 “Olmstead stakeholders” who were organized into a steering committee and six working groups. The report consisted mainly of descriptions of existing policies and programs in various state agencies; it did not include specific goals, timetables, or funding strategies. In 2003, the Illinois General Assembly enacted legislation requiring the governor to appoint a new advisory committee to assist in developing a “Disability Services Implementation Plan.” The legislation specified that the governor’s report should include the implementation plan itself, information on the number of people with disabilities who may be eligible to receive services under the plan, estimated costs of programs and services to be provided under the plan, and any necessary changes in state policies, laws, or regulations. The implementation plan was to be submitted to the legislature by November 1, 2004. As of that date, however, the advisory committee had not yet been convened.

When Illinois does move forward with an *Olmstead* implementation plan, key policy challenges will include program costs, accessibility of community-based services, and quality of care (see GAO 2001, 2003). The state will also have to struggle with disputes over “reasonable modifications” versus “fundamental alterations.” Various documents from the original *Olmstead* steering committee and working groups reflected consensus on the broad objective of achieving greater integration of people with disabilities into the community. At the same time, there remained disagreements among stakeholders on some key issues: the degree of “institutional bias” in existing state policies; whether resources should be shifted away from institutional care; and whether the state’s ultimate goal should be to replace the entire system of institutional long-term care with community-based services. Resolving these issues will require a much stronger knowledge base about disabled individuals who are at risk of institutionalization, as well as about the cost-effectiveness of various types of community-based care (see Doty, 2000).

<table>
<thead>
<tr>
<th></th>
<th>Illinois</th>
<th>U.S. total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional services</td>
<td>79.6%</td>
<td>66.9%</td>
</tr>
<tr>
<td>Community-based services</td>
<td>20.4%</td>
<td>33.1%</td>
</tr>
<tr>
<td>HCBS waivers</td>
<td>19.0%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Home health services</td>
<td>1.4%</td>
<td>3.5%</td>
</tr>
<tr>
<td>Personal care services</td>
<td>0.0%</td>
<td>7.5%</td>
</tr>
<tr>
<td>Total long-term care</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

*Source:* Medstat Group, Inc., based on data from the Centers for Medicare and Medicaid Services, CMS-64 reports.
Conclusion

The issues of institutional and community-based long-term care are part of a larger set of complex policy challenges involving the disabled Medicaid population. This group consists of individuals with a wide range of personal circumstances and health conditions — including developmental disabilities, mental illness, physical impairments, and various chronic diseases (e.g., arthritis, heart disease, cancer, AIDS). Moreover, for those in the disabled eligibility category, Medicaid coverage is important for inpatient hospital services and other acute care services, as well as for long-term care (see Joseph, 2004). Policy-relevant knowledge about disabled Medicaid beneficiaries is very fragmentary, however. There is a great need for additional research on Illinois’s heterogeneous disabled Medicaid population in regard to demographic and socioeconomic characteristics, health and functional status, disabling conditions, access to care, and use of health care services.

Notes

1 It is important to note the distinction between those who receive Medicaid because they are disabled and the prevalence of disability among Medicaid beneficiaries. The disabled eligibility group does not include all Medicaid beneficiaries with disabilities. Many disabled individuals, especially children, enter the Medicaid program through other eligibility categories (see Burwell, Crown, and Drabek, 1997).


3 Medicaid coverage of institutional mental health services is very limited. Under federal law, Medicaid funds cannot be used to pay for services in “Institutions for Mental Diseases” (IMDs) for patients over age 21 and under age 65 (see Rosenbaum, Teitelbaum, and Mauery, 2002).

4 The target populations for Illinois’s other HCBS waivers are persons under age 60 with physical disabilities, elderly individuals (age 60 or over), medically fragile/technology-dependent children, people with HIV/AIDS, persons with traumatic brain injury, and disabled and elderly individuals in supportive living facilities.

5 The state agencies contributing to the report were the Department of Human Services, the Department on Aging, the Department of Public Aid, and the Illinois Housing Development Authority. For a critique of the document, see NCD, 2003.

6 Nearly all elderly Medicaid recipients are “dual eligibles” who are also enrolled in Medicare, which pays for most of their hospital care and physician services. By contrast, only about a third of disabled Medicaid enrollees under age 65 are dual eligibles (Bruen and Holahan, 2003).

References


IDHS (2002). *Community Living and Disabilities Plan.*

Chicago: Chapin Hall Center for Children at the University of Chicago.


Reester, Heidi, Radd Missmar, and Anne Tumlinson (2004). *Recent Growth in Medicaid Home and Community-Based Service Waivers.*


