



Deinstitutionalization Toolkit: **FINANCE** – in**DETAIL**

This section of the Deinstitutionalization Toolkit includes the supportive detail on the subject of Finance. The research and detailed information provide background for the Deinstitutionalization Toolkit:

➤ **FINANCE** – in**BRIEF**

Medicaid Financing for Long-Term Care for People with ID/DD

ICF/DD Program

Most people with developmental disabilities, even during the height of institutionalization, lived with families. Before 1971, families had few other options. Most residential care outside the family home was provided in large state-run facilities and financed entirely by state, local, and private funding.

In response to evidence of the horrific conditions in which people with intellectual disabilities and developmental disabilities (ID/DD) were being warehoused, Congress established the Intermediate Care Facilities for the Developmentally Disabled (ICF/DD) program as a Medicaid benefit. Unlike the mandatory programs under Medicaid, which states had to offer if they chose to participate in the Medicaid program at all, the ICF/DD program was offered as an optional Medicaid program. A state could opt to include the program in its state Medicaid plan, or it could continue to fund its institutions without federal financial participation. In exchange for federal Medicaid funds, institutions had to comply with minimum federal requirements for safety, staffing levels, appropriate active treatment, qualified professional staff, and many other conditions. Because Medicaid contributes matching payments to states, ranging from 50 percent to 83 percent, it is not surprising that, by the 1980s, all states had adopted the ICF/DD program.

The ICF/DD program focused on large state institutions. However, federal regulations and guidelines made clear that the same level of care could be delivered in small facilities and private facilities. The cost of these facilities is reimbursable under Medicaid.



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Although participation in the ICF/DD program is optional, once a state chooses to participate, it must provide the service to anyone who is entitled to the care. Anyone who meets the financial and categorical eligibility for the state's Medicaid program, and the level of care requirements for the ICF/DD, is entitled to the service.

Currently, almost all care delivered in state-operated ID/DD centers is reimbursed by Medicaid. Because the parents' income and assets are not considered in the calculation, almost all people with ID/DD are Medicaid eligible, except those who are ineligible due to excess assets or immigration status (Gettings et al. 2003).

Most states that use both state-operated and nonstate ICFs/DD have different payment rules for the two classes of facilities. States generally pay state-operated ICFs/DD their full operating costs, because paying less would mean forgoing federal matching funds without reducing state expenditures. While some states also reimburse the full costs of nonstate facilities, many have developed alternative systems, such as costs subject to a peer group ceiling, case mix adjustment, or base cost plus inflation (Merlis 2004).

Medicaid and HCBS Waiver

In 1981, Congress established the Medicaid Home and Community-Based Services (HCBS) Waiver program. The HCBS Waiver allows states to receive federal matching funds for a variety of residential and other services and supports in the community for Medicaid beneficiaries who would otherwise require institutional care.

The HCBS Waiver program allows states to *wave* specific Medicaid regulations, including the requirement to provide the same services to all eligible Medicaid beneficiaries. States can opt to cover a limited number of people or offer the services in only certain geographic locations, and they can offer different groups of people different sets of services.

In 2009, 48 states and the District of Columbia operated 125 different HCBS Waivers for people with DD, including waivers serving the broad population of people with DD and waivers targeting people with particular conditions, such as autism spectrum disorders and intellectual disabilities. The two remaining states, Arizona and Vermont, provided similar services as part of Research and Demonstration Waivers authorized by Section 1115 of the Social Security Act (Eiken 2010).



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A Medicaid HCBS Waiver gives states the option to cover services needed to help a program participant avoid institutional placement, and states can choose exactly what to offer. States, therefore, can tailor a “package” of services and the service definitions to fit the target population of the particular waiver program. Once a person is enrolled in a waiver program, however, a state may not limit access to covered services necessary to ensure the person’s health and safety.

Under the HCBS Waiver program, Medicaid DOES NOT pay for room or board. It pays only for the support services provided. States can use HCBS Waiver funds to pay for services and supports in a variety of housing settings, such as individual apartment-like settings (Supported Living Arrangements), foster homes (Special Home Placements), two-person homes (Home Individual Programs), and community group homes (Community Integrated Living Arrangements). The funds also pay for services and supports in residential schools, adolescent group homes, and community living facilities.

The small group options available under the HCBS Waiver program differ from those available through the ICF/DD program. The small ICFs/DD provide a regulated program of services in a formally certified group setting, while small group homes funded under HCBS Waiver programs permit a wide array of services that can be more flexibly tailored to individual needs and circumstances.

Programmatic Differences in Medicaid Funding for Institutions and HCBS Waiver Program Services

Q. Is there an institutional bias in Medicaid?

A. Everyone who is eligible and chooses nursing home or ICF/DD services is entitled to receive them, and Medicaid is required to provide these services. In contrast, the number of people served by HCBS Waivers can be capped and is limited by state appropriations. Many states have long HCBS Waiver waiting lists. This leads to an institutional bias in the way Medicaid dollars are allocated.

Spending for institutional care historically has exceeded spending for community care. However, the disproportionate spending on institutional care has diminished considerably in recent years. As shown in Figure 1, nationally ICF/DD expenditures as a percentage of Medicaid long-term care expenditures for people with ID/DD have been



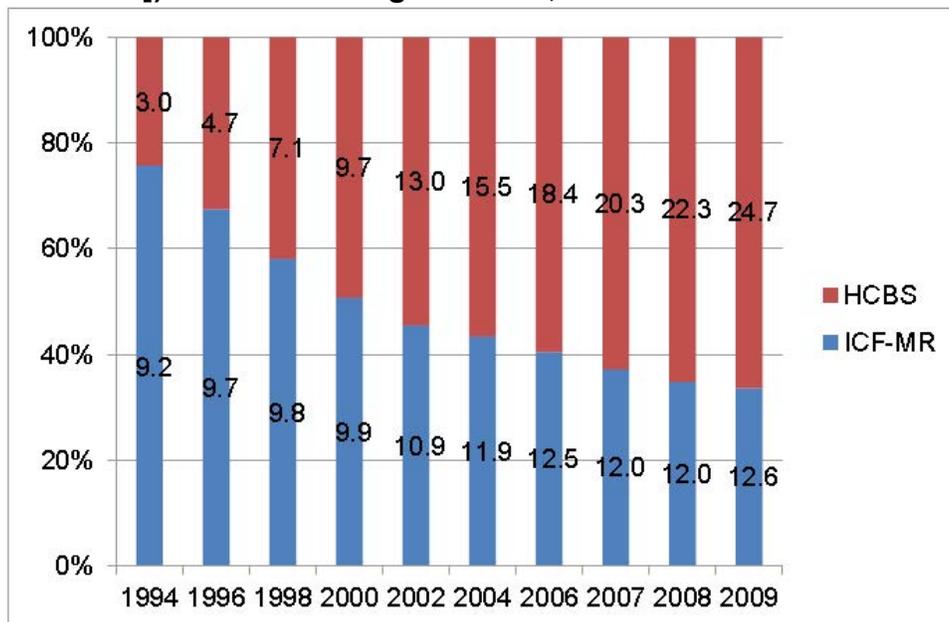
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declining as HCBS Waiver spending increases. However, states continue to apply a disproportionate amount of resources to institutions.

Figure 1. Annual Expenditures in Billions of Dollars for HCBS and ICF-MR (Intermediate Care Facilities for the [Mentally Retarded]) as a Percentage of Total, 1994–2008



Source: Data from Lakin et al. 2010, table 3.17b.

In 2008, Medicaid spent \$34.3 billion on long-term care for people with DD. ICF/DD accounted for 35 percent of the spending (\$12 billion), while HCBS Waivers accounted for 65 percent (\$22.3 billion). This shows less of an institutional bias than in 1994, when Medicaid spent 78 percent of its long-term care dollars for people with DD on ICF/DD (Lakin et al. 2010).

One group claims that institutional bias is a myth because both the ICF/DD and the HCBS Waiver programs are optional (Voice of the Retarded undated). However, their argument confuses the fact that once a state chooses to include ICF/DD services in its state plan, anyone who qualifies is entitled to the services, whereas states can limit access to HCBS Waiver services on the basis of budget or other issues. It is important to note that, although ICF/DD is an entitlement, there is no federal requirement that the state must directly provide or operate such services.



Recent Changes in Medicaid Services for People with ID/DD

Several initiatives in the past five years have sought to mitigate the institutional bias, and Medicaid funds have shifted to community-based care. However, ultimately, ICF/DD placements continue to be entitlements, while HCBS Waiver services are not.

Deficit Reduction Act (DRA) of 2005: This legislation created a new Medicaid option for states to cover certain HCBS Waiver services without being required to go through the lengthy waiver application and approval process (Tritz 2006).

Money Follows the Person (MFP), 2005: The MFP demonstration, first authorized by Congress as part of the 2005 DRA and then extended by the 2010 Patient Protection and Affordable Care Act, provides grants to states to (1) transition people living in nursing homes and other long-term care institutions (such as ICFs/DD) to homes, apartments, or group homes of four or fewer residents, and (2) change state policies so that Medicaid funds for long-term care services and supports can “follow the person” to the setting of his or her choice. As of 2010, the Centers for Medicare and Medicaid Services had awarded MFP grants to 30 states and the District of Columbia, and the demonstration is authorized through 2016 (Irvin and Ballou 2010). To ease the transition to the community, the state provides MFP participants with a richer mix of services than regular waiver participants; states receive an enhanced federal match for providing these additional services.

American Recovery and Reinvestment Act of 2009 (ARRA): ARRA provides enhanced federal matching funds that enable states to continue funding HCBS Waivers and other Medicaid services. The maintenance-of-eligibility requirement in ARRA restricts state options for reducing eligibility for services (Eiken 2010).

Community First Choice Option (2011): This proposed rule implements Section 2401 of the Affordable Care Act, which establishes a new state option to provide home and community-based attendant services and supports. The Community First Choice Option adds a new section 1915(k) to the Social Security Act that allows states to provide home and community-based attendant services and supports under their state plan. This option, available October 1, 2011, allows states to receive a 6 percentage point increase in federal matching payments for expenditures related to this option.



Community Choice Act (not enacted): The Community Choice Act, introduced in Congress in 2007 and again in 2009, would have required state Medicaid plans to cover community-based attendant services and supports. Despite advocacy efforts, the bill never got out of committee and the concept was not included in the 2010 health care reform legislation.

Ensuring Continual Financial Support of Community-Based Services

Q. With institutional care an entitlement and HCBS Waiver services optional, how have states ensured that community services will always be available?

A. Under the Medicaid HCBS Waiver program, states have considerable flexibility in determining the type of services they will provide and the number of people to whom they will provide the services. Many states have long waiting lists for services. In 2008, an estimated 122,000 people nationwide were on waiting lists for HCBS Waiver services (Lakin et al. 2010)

The availability of community services is an issue. Evaluations of the MFP grant program found that grantees have experienced challenges in finding affordable and accessible housing, securing adequate services in the community, ensuring the quality of care, and managing the risks of living in the community (Irvin et al. 2010). The media report that these services are used as a political football. For example, a September 2010 article in the *Salt Lake City Tribune* reported that the legislature cut \$2.5 million in general funds to the state Division of Services for People with Disabilities, and some of the private companies contracting with the state to do daily programs will see significant cuts, calling in question the future of the services (Lyon 2010).

This raises the question of how parents and guardians can be assured that people who are discharged from an institution can be confident that the community services identified in the discharge planning process will remain available in future years. Ensuring continued community support after people return to the community is a critical element that will require constant vigilance from both state officials and advocates.



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Social Security Programs

Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are federal programs run by the Social Security Administration that provide monthly cash payments to eligible beneficiaries. Most people with ID/DD are eligible for one or both of these income programs when they live in the community. This is a new source of income for these people, since it is not available as to people in institutions.

This income is important in terms of community living because, unlike Medicaid funding, it can be used to pay for housing and other costs not covered by Medicaid.

State Supplemental Security Programs

A number of states use state funds to supplement SSI/SSDI benefits to people with disabilities. In many states these supplements are available only to people in group homes and not to people in their own homes. In group homes, residents are usually required to pay a portion of their SSI or SSDI benefit to the agency running the home. People who live in their own home can use their SSI or SSDI payments for rent.

In many cases, funding for room and board for people with ID/DD who do not live in an institution is provided by a combination of cash benefits through the SSI/SSDI Program and each state's optional supplemental security program. This applies to both the group home and private home accommodation options.

Additional resources are available on the topic of FINANCE in the Deinstitutionalization Toolkit. These are external documents that may be accessed for a more “in**Depth**” review of the topic area.

➤ FINANCE – in**DEPTH**

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