Deinstitutionalization Toolkit: **FINANCE – in BRIEF**

**Finance and Budget**

Public financing for the supports and programs for people with intellectual disabilities and developmental disabilities (ID/DD) is provided through the Medicaid program and the Social Security Administration (SSA). This section briefly outlines the role of each funding in the deinstitutionalization process and in providing services and supports to people with ID/DD.

Understanding the complex structure and interaction between the federal and state funding of Medicaid and its Home and Community-Based Services (HCBS) Waiver program is important. Some services are mandatory and others are optional. **Waiver services are not required services under federal law, and the number of slots available, the types of services included, and the specific population to be served can be identified and capped by state governments.**

- Medicaid provides more than 75 percent of the financing for services and supports for people with ID/DD (Braddock et al., 2011).
- Another 9 percent of financing comes from direct payments to people with disabilities through SSA’s Supplemental Security Income (SSI) and Social Security Disability Insurance for Disabled Adult Child (SSDI/DAC) (Braddock et al., 2011).

SSA provides income support for people with ID/DD through its SSDI program and, most important for people with ID/DD, its SSI program. People can use this cash benefit to obtain housing and other supports. State supplements to SSI/SSDI and other state funding resources make up the rest of the public sources of revenue for service and supports for persons with ID/DD. The state supplements are often used for housing.

**Medicaid**

Each state designs and administers its own Medicaid program under federal guidelines. This program is financed jointly by federal and state governments. The federal government contributes matching payments to states ranging from 50 percent to 83 percent, based on each state’s per capita income, giving states with lower per capita
income a higher matching rate in an effort to equalize each state’s ability to fund health care services.

Medicaid dollars fund services and supports to people with ID/DD through the following state-administered programs:

- **Intermediate Care Facilities for the Developmentally Disabled (ICF/DD):** Provides a very prescriptive set of services as entitlement to people with ID/DD.
- **Home and Community-Based Services (HCBS) Waiver:** Each state program permits a wide array of services that can be more flexibly tailored to individual needs and circumstances for people with ID/DD.
- **Other State Plan Services:** This category includes physician and hospital visits, prescription drugs, certain types of therapies, some types of home health services, and other services a state may choose to offer.

Funds from state Medicaid programs may not be used to pay for room and board in community-based living accommodations.

Some of the services in each state’s Medicaid program are optional and some are mandated. States are able to limit the number of eligible people who receive HCBS Waiver support.

**Entitlement versus Optional Services**

All people who meet the financial and other eligibility criteria for Medicaid and the “level of care” criteria required for ICF/DD services are entitled to receive them. However, a state may limit the number of eligible Medicaid recipients to whom it provides HCBS Waiver services. In other words, an individual may qualify for Medicaid and meet the “level of care” criteria required for HCBS Waiver but still not receive services because the state has reached its capped limit. When the limit is reached, applicants are put on a waiting list in most states. In 2009, an estimated 122,000 people were on waiting lists for residential services. A state can modify the limit with permission from the federal Centers for Medicare and Medicaid Services (CMS). Individuals being discharged from ICF/DD are entitled to HCBS Waiver program services and therefore are exempt from waiting lists.
Because HCBS Waiver Program services are optional, they may be more vulnerable to budget cuts.

Preset waiting lists and programs with optional services and supports are a significant element of a state’s commitment to provide HCBS care to people with ID/DD who are transitioning from institutions, as well as those transitioning from ICF/DD because of their priority status.

**Recent Medicaid Changes Affecting Funding for Services for People with ID/DD**

Four Medicaid options have been established since 2005 that may affect a state’s ability to transition people from institutions or provide community-based care:

- The Deficit Reduction Act of 2005
- Money Follows the Person (MFP), 2005
- Community First Choice

For more detailed information on these Medicaid options, see the next part of Section 5 of the Deinstitutionalization Toolkit:

**Social Security Administration Programs**

SSI and SSDI are federal programs that provide monthly cash payments to eligible beneficiaries. For the person transitioning into community based services, SSI and SSDI represent a new source of financial support, because people with ID/DD living in institutions are not entitled to this benefit. Most adults with ID/DD living in the community meet the eligibility criteria for at least one (and sometimes both) programs.

**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. Residents in group homes are usually
required to pay a portion of their SSI or SSDI benefit to the agency running the home. People living 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 SSA’s SSI/SSDI programs and each state’s optional Supplemental Security Program. This applies to both group homes and private homes.

The Role of Finance in Deinstitutionalization

Successful institutional closure and transition to community living and community-based services for people with ID/DD is dependent on understanding the funding sources available and the limitations and opportunities inherent in each funding option.

Financing of services in the community is one of the most highly political aspects of deinstitutionalization. As state budgets are tightened, the continued availability of funding for community-based services will be a priority for state administrators and advocates alike. At the center of the discussion is the critical issue of what services individuals are entitled to and what services are truly optional. All funding for services and supports depends upon this decision.

For more information about finance issues, see subsequent parts of Section 5 of the Deinstitutionalization Toolkit:

- FINANCE – in DETAIL
- FINANCE – in DEPTH

References