

MEDICAID: THE NEED FOR REFORM IN LONG-TERM-CARE
SERVICES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

FACT SHEET

Medicaid Background

Medicaid was established as federal law in 1965 as a program of medical assistance for certain low income individuals and families. Medicaid (Title XIX of the Social Security Act) is financed jointly with state and federal funds, with the federal share of the cost of the program ranging from 50% to 78%. The program is administered by each state within broad federal requirements and guidelines. The state develops a state Medicaid plan which is reviewed and approved by the federal government. The federal program is administered by the Health Care Financing Administration (HCFA) which is within the Department of Health and Human Services (HHS).

The basic services which must be offered in any State Medicaid program are: inpatient hospital services, outpatient hospital services, laboratory and x-ray services (diagnostic and therapeutic), skilled nursing facility services for individuals 21 and older, home health care services, physicians services and rural health clinic services, family planning services, early and periodic screening, diagnosis and treatment services (EPSDT) for individuals under 21, and durable medical equipment. States may provide one or more of a long list of optional services. States exercise a great deal of control over eligibility levels.

States determine utilization rates and reimbursement rates to providers. Services provided by the state must be sufficient in amount, duration, and scope to achieve their purpose. States may not arbitrarily deny or reduce services to an otherwise eligible individual solely because of a diagnosis or type of illness or condition. For instance, if a person eligible for Medicaid requires extensive treatment, he or she cannot be declared ineligible because the treatment will be expensive. And the state must make provisions for assuring necessary transportation of eligible individuals to and from medical services. Such transportation may be provided and funded through other sources or paid for by Medicaid.

The ICF/MR(DD) Program

In 1971, Congress authorized the Intermediate Care Facility for the Mentally Retarded (ICF/MR) program (P.L. 92-223) to serve people with developmental disabilities in public institutions and authorized the use of Medicaid funds for such facilities. States could then use a % of federal funds in their state-run institutions, thus "saving" state funds, if they could meet the federal regulations established to upgrade the quality of care in the institutions. Private "for profit" and "not for profit" agencies built and began to operate community ICF/MR facilities, large and small, for people with developmental disabilities. The programs were "medical" and were paid for with Medicaid funds.

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Many parents did not want to place their son or daughter in a state institution or a medically oriented program and pressed for smaller, more homelike community facilities. Some states created community alternatives, such as group homes, host homes, supported living, etc. However, states had to support this community system almost totally with state funds.

The states are responsible for ensuring that ICFs/MR meet program standards. In 1980, P.L. 96-499 authorized the Secretary of Health and Human Services to conduct "look behind" surveys. In order to establish whether a facility is in compliance and meets the requirements for participation in the Medicaid program, the Health Care Financing Administration conducts onsite surveys of facilities. If a facility is found not in compliance with health and safety requirements, the Secretary has the right to cancel that facility's approval to participate in the Medicaid program.

Since 1980, HCFA has issued "look behind" procedures and has required its Regional Offices to conduct surveys of at least five percent of certified ICFs/MR. Fifty-seven full-time equivalent positions have been designated to conduct "look behinds" in ICFs/MR. Each Regional Office has at least one developmental disabilities specialist designated to participate in this effort.

In 1981, as part of the Omnibus Reconciliation Act, Congress authorized the home and community based waiver to permit states to spend Medicaid funds in the community. States had to apply for a "waiver" and could determine the number of people to be served and the services to be provided following a very complex formula and choosing services from those on the "menu". The "waiver" program grew rapidly but by FY 1986 was only in 35 states and represented only \$250 million of the \$5.2 billion budget for Medicaid ICF/MR.

As part of the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985, P.L. 99-272, Congress authorized a number of amendments to the Medicaid waiver program including a definition of "habilitation" services, special coverage for persons with physical disabilities, and extending waiver renewals for five years. COBRA also authorized optional Medicaid funded case management services, an optional phasedown for ICFs/MR facing decertification, the adoption of new ICF/MR standards and the 1985 Life Safety Code.

Eligibility for the ICF/MR(DD) Program

In addition to persons with mental retardation, persons with "related conditions" are eligible for Medicaid funded ICF/MR and home and community based waiver services. Persons with related conditions are defined as:

"persons who have a severe, chronic disability that meets all of the following conditions: (1) the disability is attributable to (a) cerebral palsy, epilepsy, or (b) any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required

for these persons; (2) it is manifested before the person reaches age 22; (3) it is likely to continue indefinitely; (4) it results in substantial functional limitations in three or more of the following areas of major life activity: (a) self-care; (b) understanding and use of language; (c) learning; (d) mobility; (e) self-direction; (f) capacity for independent living."

Findings

In spite of the changes in philosophy, technology, and "best practice" for providing services to persons with severe disabilities, the Medicaid program still contains an "institutional bias" and makes it very difficult for states to use federal funds for home and community services.

Between 1977 and 1986, the institutional census declined from 149,176 to 100,421. For FY 86, 75% of ICF/MR reimbursements went to state operated institutions with an average per diem cost of \$127. Thirteen per cent of ICF/MR reimbursements went to large "facilities" with 16 or more residents. As a higher number of people were served in the community with state funds, the "institutional bias" of Medicaid (including nursing homes) became more obvious and more unacceptable to parents, advocates, community providers, and state governments.

Using a definition of 15 or fewer persons in a "facility" to define "small", and over 15 persons to define "large", in 1986 only 13 states have reached financial parity for "small" facilities: Alaska, Arizona, California, Colorado, D.C., Florida, Indiana, Michigan, Montana, Nebraska, New Hampshire, Rhode Island, and Vermont. Even in these states, the existing federal regulations are making it very difficult to develop home and community services which assure maximum independence, productivity, and community integration.

There has been a significant decrease in the proportion of children and youth among the residents of ICFs/MR. In 1977, persons under 22 years of age made up 35.6% of the ICF/MR population; in 1982, that population had dropped to 22.6%, a much faster decline than in the general population.

The number of children with disabilities remaining at home whose families are not seeking out-of-home placements has grown dramatically because of the entitlement provisions of P.L. 94-142, the Education for All Handicapped Children Act of 1975. Parents of most of these children do not consider an "institution" an appropriate place to live, yet they get little or no funding/support to raise their child in the natural home. They also are concerned about no entitlement to services after their son/daughter leaves public school at age 21.

Waiting lists for adult residential and "day" services are in existence and increasing in most every state. Parents in their sixties, seventies, and eighties who have always had their son/daughter with disabilities living at home in the community are being told they may need to wait three to five years for a community living arrangement for their dependent. The majority of these individuals with physical disabilities need an average of 40 hours per week of personal attendant services in order to live in their own home after a period of intensive training.

It is estimated that over 50,000 persons with developmental disabilities are residing inappropriately in nursing homes. A recent study by Illinois Governor's Planning Council for Developmental Disabilities identified 2,715 persons with developmental disabilities in nursing homes and determined that 90% were inappropriately placed. The Wisconsin Governor's Planning Council on Developmental Disabilities has determined that there are 4,153 persons with developmental disabilities in nursing homes, 80% of whom are inappropriately placed.

The five year Pennhurst Longitudinal study and extensive follow-up of deinstitutionalization in six other states consistently demonstrates that persons acquire more skills in small, community settings than in congregate care. Moreover, the persons who make the greatest gains are those individuals labelled, "severe, profound, multiply handicapped."

All studies, including one prepared by the Congressional Research Office for the Senate Finance Committee in September 1986, conclude that the cost of home and community services is equal to or less than the cost of congregate care and institutional services. There are no data to support economy of scale measures in residential facilities larger than six persons.

Recent Congressional Action

The U.S. senate held joint hearings on April 1-3, 1985, on the "Care of Mentally Disabled Persons", which reflected tales of poor quality, abuse, life-threatening situations, and death in our country's public institutions. This resulted in increased funding to HCFA for surveyors and a new emphasis on quality assurance.

Several pieces of legislation for Medicaid reform have been introduced by Senators chafee, Weicker, and Bradley and Representative Florio. Several hearings and forums have been conducted, the most recent by the Senate Finance Committee's Subcommittee on Health on September 19, 1986. Almost all of the witnesses declared that "the program is broke and needs to be fixed." Witnesses included researchers, state MR/DD agency directors, advocates, persons with disabilities, and parents. Senator Lowell Weicker stated that the program has no direction and is out of synch with all other federal legislation for persons with disabilities. He described the Medicaid program as one which "promotes segregation, isolation, and dependency" and urged the Committee to act promptly to change the direction of and incentives in the program.

UCPA Position

The UCPA Mission Statement includes the following purpose: "To equip and enable individuals with cerebral palsy and other severe disabilities to attain the fullest possible employment, productivity, and participation in an integrated community."

Medicaid reform is a top priority for UCPA in 1987. Legislation must be passed which emphasizes home and community and removes the "institutional bias" in the program. New legislation must also allow a full array of reimbursable services and supports based on individual need rather than a facility model of "one size fits all" which currently exists. Limits must be set on facility size and distances between facilities.

The new legislation must provide financial incentives for states to develop community services. states must be required to develop an "infrastructure" to support a community service system, including but not limited to independent case management/service coordination, competency based staff training, technical assistance, quality assurance mechanisms, appeal and due process protection, and a planning process with public participation.

Lastly, the new legislation must contain a value base which supports rather than supplants families and which reinforces the goals of independence, productivity and community integration as stated in the Developmental Disabilities Act of 1984, P.L. 98-527.

AIB/cc

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