86-898 EPW

Congressional Research Service
The Library of Congress

Washington, D.C. 20540

SERVICES FOR PERSONS WITH MENTAL RETARDATION AMD DEVELOPMENTAL DISABILITIES: BACKGROUND INFORMATION AND DISCUSSION OF ISSUES

Prepared for the use of the
Senate Committee on Finance

Mary F. Smith Specialist in
Social Legislation
and
Richard Price
Specialist in Social Legislation
Education and Public Welfare Division
September 16, 1986

ABSTRACT

The major source of Federal support for persons with mental retardation and developmental disabilities is the Medicaid program, title XIX of the Social Security Act. This paper describes Medicaid services and other Federal programs serving this population and discusses issues in the delivery of services to these persons.

CONTENTS

CONTENTS—Continued

SERVICES FOR PERSONS WITH MENTAL RETARDATION AMD DEVELOPMENTAL DISABILITIES: BACKGROUND INFORMATION AND DISCUSSION OF ISSUES

INTRODUCTION

Services for persons with mental retardation and related conditions are funded through a variety of Federal programs. The Medicaid program, title XIX of the Social Security Act, provides the major share of Federal resources for these persons. This paper describes the population of persons with mental retardation and related conditions, identifies the major sources of program support, and presents the amount expended. The development of services to this population is presented beginning with the movement of some persons out of large isolated custodial facilities into more socially integrated, community-based settings. Although there is steady movement to increase community services, there has also been a need expressed to maintain some level of comprehensive care in larger facilities for some of these disabled persons. Issues regarding services to this disabled population are discussed and relevant legislation is summarized.

I. HISTORY

Over the past 100 years many large institutions were built to provide care for mentally retarded persons. These institutions, which frequently served many hundreds of residents, provided 24-hour maintenance and, in some facilities, therapeutic care. The institutions generally were built in rural areas not adjacent to towns or cities, and for this reason, normal community involvement of the institutionalized residents was not generally possible. Prior to the 1950s, such institutional services were virtually the only available source of services for persons with mental retardation, and many families were encouraged by their physicians to institutionalize severely handicapped newborns at birth. A General Accounting Office (GAO) report characterized institutional care as follows:

> Until the 1960s, mentally disabled persons who could not afford private care had to rely primarily on public institutions for their care. Conditions in these institutions generally were harsh. Treatment programs were limited; living quarters were crowded; few recreational or social activities were available; and individual privacy was lacking. In general, the institutions served as custodial settings, often with unpleasant conditions, and many people remained institutionalized for years. 1/

1/ U.S. General Accounting Office. Summary of a Report. Returning the Mentally Disabled to the Community: Government Needs to do More; Report to the Congress by the Comptroller General of the United States. HRD-76-152A, Jan. 7, 1977. Washington, 1977. p. 1.

In the 1950s parents of retarded children began to organize and to encourage the development of community services so that their handicapped children could receive specialized developmental services while living at home. These parents also worked to bring about improvements in institutions. This parents' group is the Association for Retarded Citizens. The movement to improve community services and institutional conditions for mentally retarded persons was supported by President Kennedy who appointed a panel to study the issue and report to the President. The panel recommended that institutional care be restricted to those retarded persons whose specific needs can be met best by this type of service. The panel further recommended that local communities, in cooperation with Federal and State agencies, undertake the development of community services for retarded persons. Abuses and neglect of retarded institutionalized persons were reported in the press, and during the 1960s and the 1970s efforts were made nationwide to improve conditions in institutions, expand alternatives to institutionalization, and move residents from institutional to community settings. This became known as the deinstitutionalization movement.

Over the past 15 years there has been a steady decline in the number of mentally retarded persons served in public institutions. Services have been developed in the community to help provide care for persons coming out of institutions and to offer an alternative to persons who may otherwise have required institutionalization.

Several pieces of landmark legislation have been enacted by the Congress to provide services and protections for persons with mental retardation and related conditions. In 1971, Congress authorized Federal Medicaid funding for care provided in intermediate care facilities for the mentally retarded and persons with related conditions (ICFs/MR). ICFs/MR provide 24-hour care in a residential facility. The Medicaid program is a Federal-State matching program that provides medical assistance for low-income persons who are aged, blind, disabled, or members of families with dependent children. To receive funds, ICFs/MR must meet Federal certification standards established under the Medicaid program. Regulations published in 1974 (42 C.F.R. 442 subpart C) were intended to ensure a safe and therapeutic environment and include provisions for adequate staffing, health and safety requirements and minimum specifications for individual space and privacy. An updated regulation published March 4, 1986, is intended to increase the focus on active treatment of institutionalized persons and to improve the ability of State survey agencies to assess the quality of care. Today the Medicaid program is the largest source of Federal support for services provided to persons with mental retardation and related conditions.

In 1975, the Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103), included provisions intended to improve services to mentally retarded and other disabled persons in institutions. This law required that States submit a plan to eliminate inappropriate placement in institutions and improve the quality of institutional care. State plans were also required to support the establishment of community programs as alternatives to institutionalization.

Also in 1975, the Education for All Handicapped Children Act (P.L. 94-142), required States to provide educational and supportive services in the Least restrictive environment for all handicapped children ages 3 to 21.

In 1980, the Civil Rights of Institutionalized Persons Act P.L. 96-247, gave the U.S. Attorney General explicit authority to initiate and intervene in litigation involving the constitutional rights of institutionalized persons. The Attorney General is authorized to intervene if he believes that deprivation of rights is part of a pattern of denial, if the suit is of general public importance, and if it is believed that institutionalized persons are being subjected to "egregious or flagrant" conditions which deprive such persons of any rights, privileges or immunities under the Constitution or laws of the United States.

II. BACKGROUND INFORMATION

A. Definition of the Target Population

Medicaid law authorizes federal support for certain institutional services for "the Mentally retarded or persons with related conditions." Mental retardation is defined by the American Association of Mental Deficiency as significantly subaverage intellectual functioning existing with deficits in adaptive behavior and manifesting during the developmental period (during childhood or adolescence). The current Medicaid regulation defining "persons with related conditions" is based on the previous and current definitions of "developmental disability" as set forth in the Developmental Disabilities Act.

A 1974 Medicaid regulation issued to cover care in ICFs/MR defined "persons with related conditions" by referencing the definition of developmental disability as set forth in a 1970 statute. 2/ This definition was originally based on specific impairments including mental retardation, cerebral palsy, epilepsy, and related neurological conditions. The current definition of developmental disability enacted in 1978 is a functional definition that describes the adaptive capacity of eligible persons, but does not include specific impairments. A developmental disability is currently defined under

---

2/ Developmental Disabilities Services and facilities Construction Act.

the Developmental Disabilities Act as a severe, chronic disability which begins by the time a person is a young adult and which substantially limits the person's ability to function independently. The statutory definition states: [3]

> The term "developmental disability" means a severe, chronic disability of a person which:
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
> (B) is manifested before the person attains age 22;
> (C) is likely to continue indefinitely;
> (D) results in substantial functional limitations in three or more of the following areas of major life activity; self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and
> (E) reflects the persons' need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Because this definition does not include specific impairments, it can be interpreted to include mental illness, and mental illness is not covered under Medicaid's ICF/MR benefit. Medicaid provides funds for services to the mentally ill apart from the ICF/MR program. Therefore, the Health Care Financing Administration (HCFA) promulgated a new regulation to define "persons with related conditions." (51 Federal Register 19181, published May 28, 1986.) This definition includes components of the former and the current definitions of developmental disability and specifically excludes mental illness:

> "Persons with related conditions" means individuals who have a severe, chronic disability that meets all of the following conditions:
> (A) It is attributable to:
> cerebral palsy or epilepsy or 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.

---

[3] Section 102(7) of the Developmental Disabilities Assistance and Bill of Rights Act.

(B) It is manifested before the person reaches age 22.
(C) It is likely to continue indefinitely.
(D) It results in substantial functional limitation in three or more of the following areas of major life activity: self-care, understanding and use of language, learning, mobility, self-direction, capacity for independent living.

In summary, it might be said that the Medicaid program's support for persons with conditions related to mental retardation is intended for persons whose conditions cause severe intellectual or behavioral deficits requiring services similar to those required by mentally retarded persons.

This paper will use the term persons with mental retardation or developmental disabilities (MR/DD) to mean persons who are eligible for a variety of Federal programs; the term includes those mentally retarded and persons with other related conditions that are eligible for Medicaid services as described above.

III. MEDICAID SERVICES FOR MR/DD PERSONS

The major source of Federal support for care for MR/DD persons is the Medicaid program, authorized under title XIX of the Social Security Act. The Medicaid program is a Federal-State matching program which provides medical assistance for low-income persons who are aged, blind, disabled, or members of families with dependent children. Eligibility for Medicaid is generally linked to actual or potential receipt of cash assistance under the Federal Supplemental Security Income (SSI) program for the aged, blind, and disabled or the federally assisted Aid to Families with Dependent Children (AFDC) program. Most MR/DD persons who became eligible for Medicaid do so on the basis of their disabled status under SSI. It should be noted that under SSI disability rules, an individual is not considered to be disabled if he or she is able to engage in "substantial gainful activity" (SGA), which the Secretary of Health and Human Services (HHS) has defined as average counted earnings of $300 or more per month. For children under 18, disability must be of comparable severity.

All States cover the "categorically needy" under their Medicaid programs. In general, these are persons receiving cash assistance under SSI or AFDC. States have the option of limiting Medicaid coverage of SSI recipients by requiring then to meet any more restrictive eligibility standard that was in effect on January 1, 1972 (before implementation of SSI). These States are commonly referred to as "209(b) States" in reference to the statutory provision which gives them the option to use their 1972 eligibility standards instead of SSI's. States choosing the more restrictive criteria must allow applicants to deduct medical expenses from income in determining eligibility. States may also cover certain additional persons as categorically needy who do not actually receive cash assistance. These might include persons who would be eligible for cash assistance, except that they are residents in medical institutions (such as skilled nursing facilities or intermediate care facilities). Many MR/DD persons who become eligible for medical assistance under Medicaid are considered categorically needy recipients. 4/ It should be noted that under SSI (and therefore Medicaid) eligibility rules, an institutionalized, individual is no longer considered to be living in the same household as his/her parents or spouse after the first full month of institutionalization, and income of the parents or spouse is not considered as available, unless actually contributed, for the care of the institutionalized person.

States are required to offer the following services to categorically needy recipients under their Medicaid programs: inpatient and outpatient hospital services; physician services; laboratory and x-ray services; skilled nursing facility (SNF) services for individuals over 21; home health services for those entitled to SNF care; early and periodic screening, diagnosis and treatment (EPSDT) for individuals under age 21; and family planning services and supplies. States may also provide coverage for a broad range of optional

---

4/ Generally MR/DD persons who are categorically needy recipients are permanently and totally disabled individuals eligible to receive SSI assistance. In addition, MR/DD persons may become eligible for Medicaid assistance if they are "medically needy." The medically needy are aged, blind, disabled, or members of families with dependent children (1) whose income and/or resources are slightly in excess of standards for SSI or AFDC cash assistance, and (2) who incur medical expenses which reduces their income to the State's medically needy income eligibility level.

services, including drugs, intermediate care facility (ICF) services, and eyeglasses. States are permitted to establish Limitations on the amount of care provided under a service category (such as limiting the number of days of covered hospital care or the number of physician services). Because States have flexibility in defining the services that will be covered under their Medicaid plans, the actual services that an MR/DD Medicaid recipient receives will therefore vary from State to State.

In general, HCFA, which, together with the States, administers the Medicaid program, does not collect data on the utilization by MR/DD eligible recipients of most categories of services covered by the States in their Medicaid programs. However, HCFA does report data on certain institutional services frequently used by this population. In addition, data from a special study on services used by the MR/DD population are discussed later in this paper.

A. Institutional Services Covered under Medicaid for MR/DD Individuals

Under Medicaid, States provide institutional services to MR/DD persons primarily through facilities known as intermediate care facilities for the mentally retarded (ICFs/MR). Medicaid law defines in section 1905(c) of the Social Security Act an ICF as an institution which: (1) is licensed under State law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing facility is designed to provide, but who, because of their mental or physical condition require care and services (above the level of room and board) which can be made available to them only through institutional facilities; (2) meets standards prescribed by the Secretary as he finds appropriate for the proper provision of this care; (3) meets standards of safety and sanitation which arc established by the Secretary in regulation in addition to those applicable to nursing homes under State law; and (4) meets requirements for protection of patients' funds.

Medicaid statute also specifies in section 1905(d) that intermediate care facility services may include services in a public institution (or distinct part thereof) for the mentally retarded or persons with related conditions if, among other things: (1) the primary purpose of the institution (or distinct part thereof) is to provide health or rehabilitative services for mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary; and (2) the mentally retarded individual is receiving active treatment. These facilities are known as ICFs/MR.

In FY 1985, only one State, Wyoming (in addition to Arizona which is operating an alternative demonstration program), did not cover ICF/MR services under its Medicaid program. According to HCFA approximately 150,000 persons were served in ICFs/MR in FY 1985. Federal and State expenditures for ICF/MR care totaled $4.7 billion in FY 1985.

Some MR/DD persons arc also served under Medicaid in ICFs and SNFs, that are not ICFs/MR. According to HCFA, ICFs and SNFs are generally not considered to be appropriate settings for care for MR/DD individuals. However, if an MR/DD individual has reached the capacity of his intellectual and social development or requires primarily skilled Medical care, then on ICF or SNF may be an appropriate setting for his care. HCFA estimates that up to 10 percent of residents of ICFs and SNFs are mentally retarded persons. (In FY 1985, there were 826,966 recipients of ICF care and 547,051 recipients of SNF care- According to the HCFA estimate, about 140,000 of these persons were mentally retarded.

B. Home and Community-Based Services for the MR/DD Individuals

Section 1915(c) of Medicaid law authorizes the Secretary of HHS to waive certain Medicaid requirements to allow States to provide a broad range of home and community-bated services to individuals who would otherwise require, and have paid for by Medicaid, the level of care provided in a SNF or ICF. Home and community-based services waivers are frequently referred to as 2176 waivers after the section in the Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, which authorized them. Although certain home and community-based services could be covered by the States under their Medicaid plans prior to the amendment, the 1981 legislation provides States with increased flexibility to offer an expanded range of such services, to determine individuals to be covered, and to define the geographic areas to be served.

Under the this waiver authority, HCFA is allowed to waive two specific Medicaid requirements: (1) a requirement that Medicaid services be available throughout a State, and (2) a requirement that covered services be equal in amount, duration, and scope for certain Medicaid recipients. By allowing the Secretary to waive these requirements, States are given flexibility to offer selected 2176 home and community-based services in only a portion of the State, rather than in all geographic jurisdictions as would be required absent the waiver, and to offer selected services to certain State-defined individuals eligible for Medicaid assistance, rather than offering such services to all eligible individuals.

In order to receive approval for a waiver, States must provide a number of assurances to the Secretary, including one requiring that the estimated average per capita expenditure for medical assistance under the waiver for those receiving wavered services in any fiscal year not exceed 100 percent of the average per capita expenditure chat the State reasonably estimates would have been incurred in that year for that population if the waiver had not been granted. In addition, States must assure that necessary safeguards (including adequate standards for provider participation) have been taken to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended for these services.

States may cover the following services under 2176 waivers: case management, homemaker/home health aide services, personal care, adult day health, habilitation services, respite care, 5/ and such other services requested by the State and approved by the Secretary. These other services have included home modifications, non-medical transportation, nutritional counseling, and congregate and home-delivered meals.

The client groups most frequently served by States under the waiver have been the aged/disabled and MR/DD. Since the inception of the program, HCFA has approved 144 waivers in 47 States. As of August 25, 1986, 104 approved waivers are active in 44 States. Of the total active waivers, 46 are currently serving MR/DD persons in 35 States. A HCFA survey of active waivers as of September 30, 1985, showed that 21,109 MR/DD persons were being served at that time. The most frequently offered services to MR/DD individuals under the waiver program have been case management, habilitation, and respite care. A provision in the Consolidated Omnibus Budget Reconciliation Act of 1986, P.L. 99-272, defined habilitation services, for purposes of 2176 waivers, as services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings, including prevocational, educational, and supported

---

5/ See Glossary at Appendix A for definitions of these terms.

employment services. 6/ Habilitation services provided under the waiver authority cannot include special education and related services as defined in the Education of the Handicapped Act which otherwise are available through a local educational agency, or vocational rehabilitation services 7/ which otherwise are available through a program funded under the Rehabilitation Act of 1973, as amended.

C. Standards for Assuring Quality Care for MR/DP Medicaid Recipients

As noted above, the Medicaid statute requires that services provided to MR/DD recipients, whether in the community or an institution, meet certain standards designed to protect the health and safety of the recipients of services.

1. Home and Community-Based Waiver Services

For home and community-based services provided under 2176 waivers, final regulations issued by HCFA March 13, 1985, require States to provide assurances that necessary safeguards have been taken to protect the health and welfare of the recipients of these services. The regulations specify that safeguards include adequate standards for all types of providers that furnish services under the waiver as well as standards for board and care homes where a significant number of SSI recipients are residing or likely to reside and where home and community-based services say be provided. If the State has licensure or certification requirements for any services or for individuals who furnish

---

6/ Ibid.

7/ Ibid.

these services under the waiver, it must assure HCFA that the standards in the licensure or certification requirements will be met. The preamble to interim regulations on the waiver program pointed out that the regulations do not attempt to define these safeguards or to prescribe how they are to be developed. Rather they leave to the State the responsibility for determining what the necessary safeguards are, to define them or specify how they will be developed and implemented, and to explain how they satisfy the statute.

2. ICF/MR Services Under Medicaid

Medicaid statute requires ICFs/MR to meet certain definitional requirements as well as standards prescribed by the Secretary for safety and sanitation and for the proper provision of care. These standards were originally published by the Secretary in regulations in 1974 and have not been significantly revised since then. HCFA has proposed a general revision of these standards in a rule published March 4, 1986. According to HCFA, this revision is intended to increase the focus on the provision of active treatment services to clients, clarify Federal requirements, maintain essential client protections, and provide State survey agencies with a more accurate mechanism for assessing quality of care.

Current standards prescribe requirements for staffing, resident Living areas, residents' rights, medical, nursing, and dental services, food and nutrition services, among others, which an ICF/HE must meet in order to participate in Medicaid.

Regulations also define in greater detail certain other requirements contained in Medicaid law for ICFs/MR. For example, regulations require that active treatment provided by ICFs/MR include: (1) regular participation by the recipient in professionally developed and supervised activities, experiences, or therapies; (2) an individual written plan of care that sets forth measurable goals or objectives for desirable behavior and a program for reaching them; (3) an interdisciplinary professional evaluation; (4) reevaluation at least annually by the staff involved in carrying out the resident's individual plan of care to review progress made toward meeting the plan's objectives, the appropriateness of the plan, continuing need for institutional care, and consideration of alternative methods of care; and (5) an individual post institutional plan of care that is developed before discharge and that specifies appropriate services, protective supervision, and other follow-up services needed in the resident's new environment.

States must certify that ICFs/MR meet these various requirements and standards before Federal payments may be made for care provided to eligible recipients in these institutions. Medicaid law requires the State Medicaid agency to contract with a State survey agency to determine, through inspection, whether facilities meet the requirements for participation in the Medicaid program. The survey agency may certify a facility that fully meets requirements and standards for up to 12 months. Survey agencies say also certify a facility for participation if it is found to be deficient in one or more standards if the deficiencies, individually or in combination, do not jeopardize the health and safety of patients and if the facility submits an acceptable plan of correction for achieving compliance within a reasonable period of time. A facility with deficiencies that do not jeopardize the patient's health and safety may continue to be certified under Medicaid for a period of up to 12 months while it corrects the deficiencies.

In the Omnibus Reconciliation Act of 1980, P.L. 96-499, Congress authorized the Secretary of HHS to "look behind" a State's survey of nursing homes and make an independent and binding determination regarding a facility's compliance with program requirements and standards. If the Secretary finds that a facility fails to meet program requirements and standards, he is authorized to terminate the facility's participation until the reason for the termination has been removed and there is reasonable assurance that it will not recur. In FY 1985, HCFA completed 464 look-behind surveys of ICFs/MR. In that year, 72 facilities, or 15 percent of the total number inspected by HCFA, were notified of some form of possible adverse action by HCFA. Eight facilities were actually terminated or voluntarily withdrew their participation following HCFA inspections. In FY 1986, HCFA has completed 514 look-behind inspections as of August 1, 1986, and 80 facilities, or 12 percent of the total inspected, have been notified of the possibility of some kind of termination proceedings.

In addition, before the enactment of P.L. 96-499, if a State survey agency made a determination that a facility could not comply with requirements and standards for care, the only available sanction was to terminate the facility's provider agreement. P.L. 99-499 provided HCFA and State Medicaid agencies with an alternative intermediate sanction for deficient ICFs and SNFs. When a finding is made that a facility no longer substantially meets the law's requirements and standards of care, and deficiencies do not immediately jeopardize the health and safety of the facility's patients, the Secretary and/or State nay, instead of terminating the facility's participation in the program, refuse to make payments on behalf of eligible individuals later admitted to the facility. However, if it is determined that the deficiencies do immediately jeopardize the health and safety of the facility's patients, the Secretary or State must terminate the facility's participation in the program. If the decision is made to deny program payment instead of terminating a facility's participation, the facility must achieve substantial compliance with program requirements or be found to have made a good faith effort to correct its deficiencies by the end of the 11th month following the month when a decision is made to deny payment. Final regulations implementing these provision were published July 3, 1986, and became effective August 4, 1986.

The Consolidated Budget Reconciliation Act of 1985 (COBRA), P.L. 99-272, enacted April 7, 1986, provided States additional options under which ICFs/MR that are found by the Secretary to have substantial deficiencies that do not pose an immediate threat to recipients' health and safety nay remedy those deficiencies. These provisions in COBRA allow the State Medicaid agency to submit written plans Co the Secretary either to make all necessary corrections in such facilities, including staff and physical plan corrections, within 6 months of the approval date of the plan, or to reduce permanently the number of beds in certified units within 36 months of the approval date of the plan. These options apply only to correction and reduction plans approved by the Secretary within 3 years after the effective date of final regulations. Proposed regulations for these COBRA provisions were published by HCFA July 25, 1986.

IV. FEDERAL EXPENDITURES FOR PROGRAMS SERVING THE MR/DP POPULATION

It is estimated that in FY 1985, $4.7 billion in Federal funds was used to support various services for the MR/DD population. 8/ Of this Federal total, $2.7 billion or 57 percent, was used for room and board, health, and rehabilitative services delivered in ICFs/MR. The next largest Federal estimate was $930 million for Medicaid services delivered to MR/DD persons who were not in ICFs/MR.

The following services may be delivered in or out of institutions, but are primarily community-based services. Human development services accounted for $347 million and included grants to States for developmental disabilities programs and social services. State developmental disabilities services are focused primarily on community living services, employment-related activities, child development services, and case management services. State grants for

---

8/ Data in this paragraph are from: Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. University of Illinois at Chicago. July, 1985. p. 31 and 71. This research was partially supported by the National Institute of Handicapped Research, U.S. Department of Education and by the Administration on Developmental Disabilities, U.S. Department of Health and Human Services. The data for this report were obtained directly from the States and, to a lesser extent, from HCFA. This research provides the most comprehensive analysis of expenditure data for MR/DD persons by source of support.

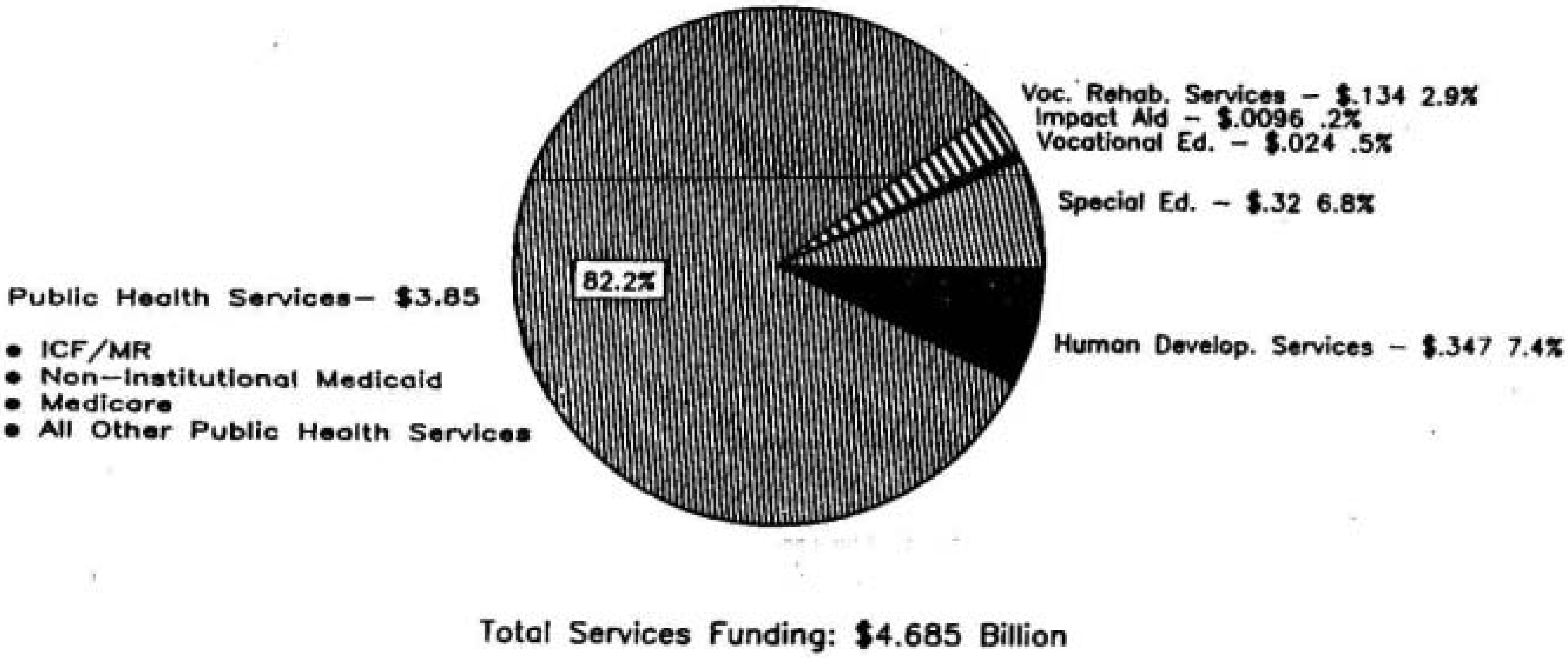
In addition to the Federal funds discussed here, States provide funding for services for the MR/DD population that is in excess of the Federal amount. The voluntary sector also provides funds for MR/DD services.

social services, authorized under title XX of the Social Security Act, may be used to assist the MR/DD population in areas such as protective services, day care services for adults, training, and employment services. For special education services to MR/DD children, $320 million in Federal dollars was expended. Vocational rehabilitation services used to train and place MR/DD adults into employment accounted for $134 million. Chart 1 shows the total Federal support for MR/DD services in FY 1985, 82.2 percent of which is used for public health services. Chart 2 shows Federal spending for public health services for MR/DD persons in FY 1985. Table 1 summarizes individual eligibility and services covered under the major Federal programs serving the MR/DD population.

In addition to Federal funds, States provide funding for services to MR/DD persons. A recent study estimates that in FY 1984, State funds accounted for 54 percent of the cost of institutional services and 70 percent of the cost of community services. 9/

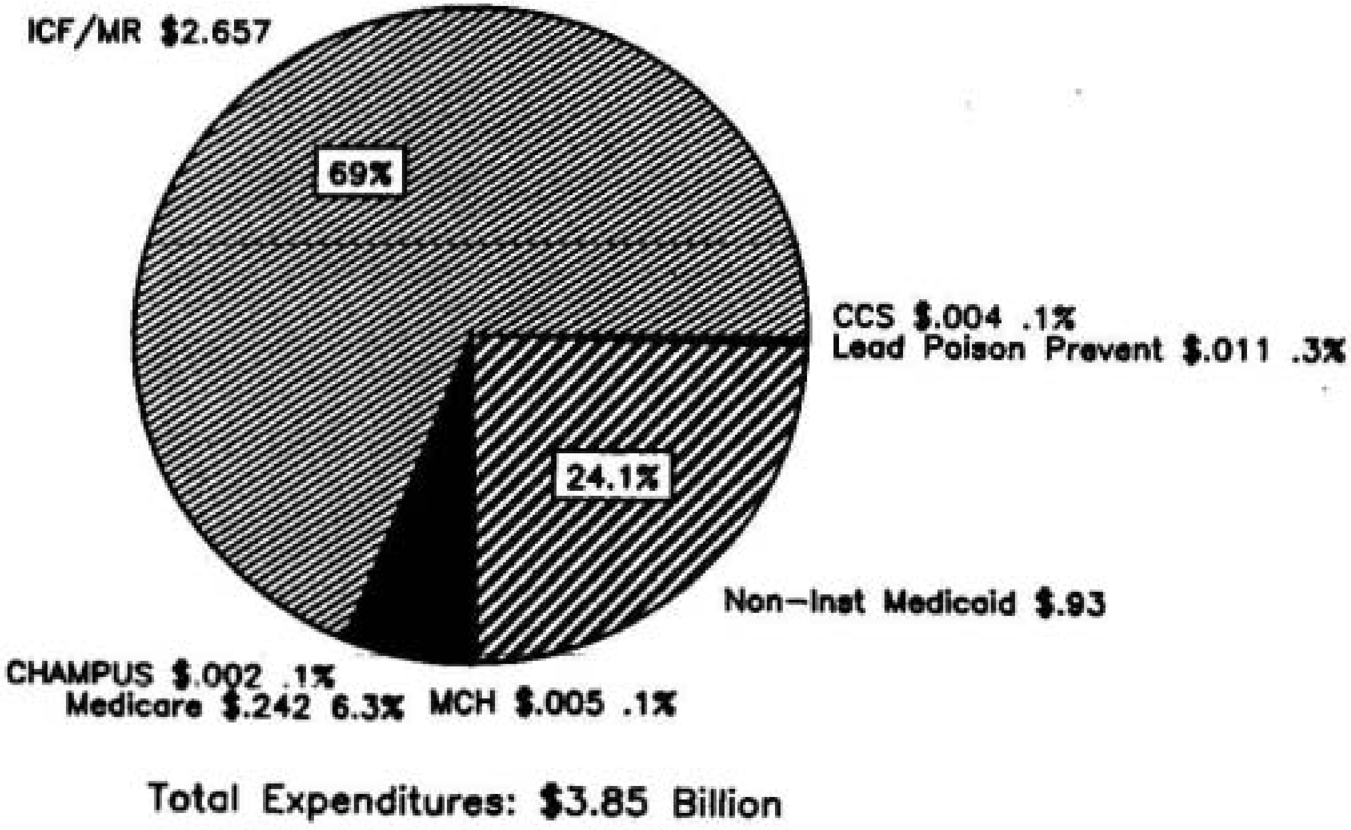
9/ Braddock, David, et al. Public Expenditures for Mental Retardation and Developmental Disabilities in the United States. State Profiles, Public Policy Monograph Series no. 5. University of Illinois at Chicago. Dec. 1984. p. 19.

CHART 1. FEDERAL SUPPORT FOR MR/DD SERVICES: FY 1985
(Dollars in Billions)



Source: Reproduced from Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. The University of Illinois at Chicago. July 1985. p. 31.

CHART 2. ESTIMATED FEDERAL SPENDING FOR MR/DD PUBLIC HEALTH SERVICES: FY 1985, BY PROGRAM
(Dollars in Billions)



Source: Reproduced from Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. The University of Illinois at Chicago. July 1985. p. 71.

TABLE 1. Major Federal Support for MR/DD Services:
Services Covered and Eligibility

Program	Services covered	Eligibility
Medicaid ICF/MR	Health and rehabilitative services, including active treatment in an institution certified as meeting various requirements and standards.	Generally, disabled persons receiving cash assistance, or if in an institution, eligible to receive cash assistance under SSI, or the medically needy who incur medical expenses which reduce their income to the State's eligibility level.
Medicaid Hoc ICF/MR	Services which States are required to offer to certain recipients, including inpatient hospital services, physicians services, laboratory and x-ray services, and other optional services which States may cover such as prescription drugs, eyeglasses.	Generally disabled persons receiving cash assistance under SSI, or the medically needy.
Human development services (delivered in or out of institutions)	Developmental disabilities services including child development, employment-related services, alternative community living arrangement services, and case management services. Also included are developmental disabilities interdisciplinary training and protection and advocacy grants.	Persons meeting the definition of developmental disability.
	This category also includes a wide range of social services under the Social Services Block Grant, as well as Child Welfare Services, Headstart, and the Poster Grandparent Program.	These programs are generally available to MR/DD and other persons.

TABLE 1. Major Federal Support for MR/DD Services: Services Covered and Eligibility—continued

Program	Services covered	Eligibility
Special education (delivered in or out of institutions)	Includes funds for special education and related services for handicapped children in State-operated or State-supported schools; funds for State grants to provide special education services to all handicapped children; and funds for preschool incentive grants. Special education includes classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions. Related services include transportation and such developmental, corrective, and other supportive services as nay be required, as well as early identification and assessment of handicapping conditions in children.	Handicapped children means children with the following disabilities who require special education and related services: mental retardation, hearing impairments, speech or language impairments, visual impairments, serious emotional disturbance, orthopedic impairments, specific learning disabilities, other health impairments.
Vocational rehabilitation (delivered in or out of institutions)	Includes Federal allotments to State vocational rehabilitation agencies to provide comprehensive services to handicapped individuals including evaluation, physical and mental restoration, vocational training, special devices required for employment, job placement, follow-up services, and any other services necessary to make the handicapped person	Handicapped individual means a person with a physical or mental disability which results in a substantial handicap to employment; the individual must be expected to benefit in terms of employ-ability from the services provided.

V. COSTS AMD NUMBER OF PERSONS SERVED IN RESIDENTIAL FACILITIES

A. Overview

There is no precise figure available of the number of MR/DD persons in the U.S. or of the number of mentally retarded or persons with related conditions eligible for Medicaid. The numbers presented below are based on persons served in different types of facilities, but do not include persons living with their families, many of whom would request services if there were additional community-based residential services available. There is lack of uniformity in the numbers presented below because data are from different agencies and represent different years. The numbers also overlap. The type of facilities that may care for MR/DD persons may be licensed by the State to provide some level of care and services. Among licensed facilities, some may be certified by Medicaid as ICFs/MR. Licensed facilities, including ICFs/MR, may be public or private. Unlicensed facilities would necessarily be private.

In FY 1982, 243,669 persons were served in licensed care facilities. This number includes public and private facilities, but does not include MR/DD persons in unlicensed facilities. In FY 1984, 109,827 persons were served in public institutions, most of which are ICF/MR certified. This number does not include persons served in private facilities. The number served in ICFs/MR, 158,616 in FY 1984, includes public and private ICFs/MR, but does not include those in facilities not certified to receive ICFs/MR funding. It is estimated that the number of persons potentially eligible for ICF/MR services is at least double the number currently receiving such services. Annual costs of ICF/MR services are presented and per diem ICF/MR costs are compared with costs in facilities not certified as ICFs/MR.

B. Estimate of Total Number of MR/DD Persons

A recently-published study of the total number of persons who could be eligible for ICF/MR services indicates that about 377,000, or slightly more than double the present number of persons, are potentially eligible. 10/ This number is baaed on an estimate of the number of severely and profoundly retarded persons in the U.S., on the assumption that ICF/MR services are most appropriate for this population. If mildly and moderately retarded persons are also target populations of Medicaid-funded community-based services, the potential eligible population could approximate 2 million, according to the author of the article cited above.

C. Number and Characteristics of MR/DP Persona in Licensed Care Facilities

A 1982 survey indicated that in that year there were 243,669 MR/DP persons served in gone type of facility specifically licensed for the care of mentally retarded people: public or private institutions, nursing horses, supervised

---

10/ Lakin, Charles and Bradley Hill. Target Population, from An Analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF/MR) Program, Center for Residential and Community Services, University of Minnesota, Sept. 1985, p. 2-37.

group or individual living arrangement, foster care, and boarding homes. Table 2 shows the number of persons served by size of facility and the number of facilities in each size category.

TABLE 2. Number of Persons with Mental Retardation or Related Conditions Served in State Licensed Residential Facilities as of June 30, 1982

Number of beds in facility	Number and (percent) of persons served	Number of facilities
1-6 a/	33,188 (14)	10,469
7-15	30,515 (12)	3,393
16-63	25,691 (10)	1,098
64-299	45,709 (19)	495
300+	108,566 (45)	178
Total	243,669 (100)	15,633

a/ Facilities of six beds or fewer are mostly foster care arrangements.

Source: Lakin, Charles, Ph.D. Center for Residential and Community Services, University of Minnesota. From 1982 National Survey of Residential Facilities for Mentally Retarded People. (Survey supported by a grant from the Health Care financing Administration (HCFA).)

D. Public Institutions

Large institutions originally built to provide 24-hour care to mentally retarded persons became, in many places, the only available residential facility for persons with severe cerebral palsy, uncontrolled epilepsy, autism and certain other severe, chronic or multiply handicapping conditions. Facilities providing institutional care for these MR/DD persons range in size from 16 to 2,000 beds, although about one half of all institutionalized MR/DD persona are in State-operated facilities of 300 beds or over.

Over the past decade, there has been a nationwide effort to move less severely disabled persons out of large public institutions and into small community-based facilities. As a result, the population of public institutions decreased 42 percent between 1970 and 1984, from 189,546 to 109,827. 11/

As disabled persons were transferred from institutions to community settings over the past decade, those remaining in public institutions tended to be the most severely handicapped persons. In 1982, 57.2 percent; of the residents of public institutions were profoundly retarded, 23.8 percent: were severely retarded, 12.3 percent were moderately retarded and 6.1 percent were mildly retarded. 12/ Those remaining in institutions were also more likely to have multiple handicaps. Of the institutionalized retarded persons: 12 percent were also blind; 6 percent were deaf; 41 percent had epilepsy; 21 percent had cerebral palsy; and 36 percent had an emotional handicap. In 1976, 34.4 percent of the residents of public residential facilities were multiply handicapped; this number had increased to 43.1 percent by 1982. The percentage of those with an emotional handicap nearly tripled during that period from 13.3 to 36.0 percent. In summary, of those residents remaining in public institutions, 81 percent are severely or profoundly retarded, 43 percent are multiply handicapped, and 36 percent have an emotional handicap.

The functional level of these institutionalized residents is characterized as follows:

- 29 percent could not walk without assistance;
- 61 percent could not dress without assistance;
- 40 percent could not eat without assistance;
- 28 percent could not understand the spoken word;

11/ See appendix 8 for the average daily population of persons in public residential facilities from 1970-1984.

12/ Data from Charles Lakin, Ph.D. University of Minnesota.

- o 55 percent could not communicate verbally; and
- o 40 percent were not toilet-trained.

E. Program Costs and Persona Served in ICFs/MR

In FY 1984, the most recent year for which such data are available, 158,616 MR/DD persons were served in the ICF/MR program at a cost of $2.6 billion in Federal expenditures. Table 3 indicates that ICF/MS expenditures, as a percentage of total Federal Medicaid expenditures, increased from 1 percent when the program began in FY 1972 to 13 percent in FY 1984. Although the ICF/MR program absorbed 13 percent of the Federal Medicaid dollars in FY 1984, its beneficiaries accounted for less than 1 percent of the persons served under the Medicaid program. The ICF/MR program grew rapidly in the first decade, and experienced an average annual rate of increase of over 18 percent between FY 1972 and FY 1981. This rate of growth has declined in more recent years, and averaged an annual 9 percent increase between FY 1981 and FY 1985. In FY 1985, there was only a 3 percent growth rate.

There is great variation in the extent to which States participate in the ICF/MR program. Of all beds licensed or operated by the States for care of the MR/DD population, the percentage of ICF/MR-certified beds ranged from a high of 98 percent in Minnesota to a low of 17 percent in West Virginia. Appendix C shows this percentage by State. It is estimated that in FY 1986, approximately 77 percent of the Federal ICF/MR funds are being used in public residential facilities and 23 percent are being used in private residential facilities. 13/

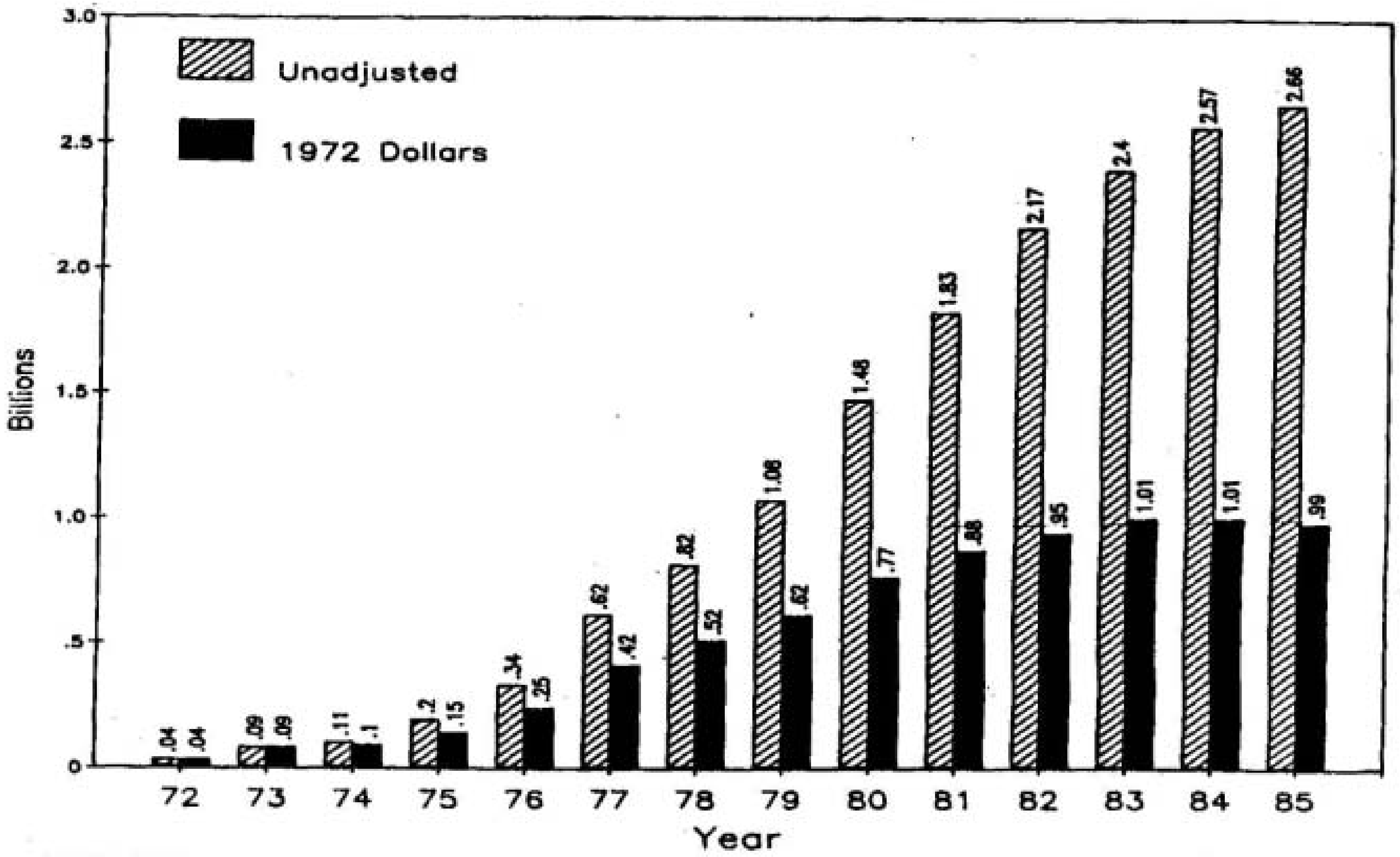
13/ Braddock, David, et al. Public Expenditures for Mental Retardation and Developmental Disabilities in the United States. State Profiles, Second Edition, FY 1977-FY 1986. Public Policy Monograph Series no. 29. University of Illinois at Chicago. Sept. 1986. p. 63.

TABLE 3. History of ICF/MR Reimbursements
($ in thousands)

Fiscal Year	Total Medicaid Federal Funding	ICF/MR Reimbursements Federal Share	ICF/MR as % of Total Federal Medicaid	ICF/MR Residents	Total Medicaid Recipients
1972 (est.)	$3,527,467	$36,872	1.05%	12,188	18,311,978
1973	4,838,260	92,181	1.91	30,472	19,998,566
1974	5,590,413	113,835	2.04	40,008	22,008,607
1975	6,873,890	195,174	2.84	55,033	22,413,309
1976	7,913,889	336,904	4.26	85,633	24,666,253
1977	9,114,477	615,337	6.75	100,823	22,929,873
1978	10,066,544	817,393	8.12	100,496	22,206,577
1979	11,458,642	1,080,462	9.43	115,168	21,536,715
1980	13,291,174	1,479,285	11.13	125,328	21,710,516
1981	15,739,472	1,833,670	11.65	173,764	21,979,638
1982	16,743,303	2,170,314	12.96	154,305	21,936,446
1983	17,751,945	2,395,178	13.49	155,194	21,493,000
1984	19,884,000	2,572,336	12.94	158,616	22,487,000
1985	22,116,000	2,657,000	12.01	—	23,114,000

Source: Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7, University of Illinois at Chicago, July 1985. p. 72.

CHART 3. FEDERAL ICF/MR REIMBURSEMENTS: FY 1972 - 1985



Source: Reproduced from Braddock, David, Ph.D. Federal Spending for Mental Retardation and Developmental Disabilities. Public Policy Monograph Series no. 7. The University of Illinois at Chicago. July 1985. p. 74.

F. Per Diem Costs by Type of Facility

Numerous studies have attempted to identify the per diem cost differential between institution and community-based residential programs for the MR/DD population. A recent assessment of 11 of these studies shows that while there were lower average per dies costs for community services, there was a wide and unexplained range of costs even in supposedly comparable settings with comparable clients. Higher than average costs were found for persons with severe and/or multiple disabilities and for school age disabled persons, regardless of service settings. As MR/DD persons moved from institution to community care settings, responsibility for funding of services shifted from Federal to State and local governments. Generally higher functioning levels were found among MR/DD clients served in the community, and there was an overall association between community programs and improved client outcomes. 14/

Facilities certified as ICFs/MR may maintain higher standards of care than non-certified facilities, and facilities of less than 16 beds tend to serve the less severely disabled persons. According to one major study (see Table 4), the most expensive facility was the State-operated ICF/MR with 16 or more beds. The ICF/MR-certified institutions of 16 or more beds provide services for persons who tend to be very severely impaired. The per patient per diem cost of a State-operated ICF/MR ranged from a high of $145 per day in the District of Columbia to a low of $40 per day in Kansas and Oklahoma. 15/ The cost of a

---

14/ Kotler, Martin, et al. Synthesis of Cost Studies on the Long-Term Care of Health-Impaired Elderly and Other Disabled Persons: Executive Summary. Macro Systems, Inc., Silver Spring, Maryland, Sept. 16, 1985. See also footnote

15/ See appendix D for ICF/MR per diem rates by State. The variation in per diem rate is based on differences in kinds and amounts of services provided and differences in salaries and other institutional expenses, according to a HCFA official.

privately operated non-certified residence of 15 beds or fewer was the Least expensive option at $25 per day; this amount did not include the cost of community services received away from the residence.

TABLE 4. Per Diem Costs for Persons with Mental Retardation or Related Conditions Served in State Licensed Residential Facilities, FY82

Number of beds	Public facilities	Private facilities
16+ beds		
ICF/MR certified Non-	$87	$51
certified	73	39
1-15 beds		
ICF/MR certified Non-	82	62
certified	33	25

Source: Lakin, Charles, Ph.D, Center for Residential and Community Services, University of Minnesota. Telephone conversation with the author, June 21, 1985. Data from 1982 National Survey of Residential Facilities for Mentally Retarded People.

The differences in employee salaries and benefits account for some of the variation in per diem costs. Employees of State institutions tend to be unionized and to receive more employee benefits than do persons delivering care in community facilities, e.g., a 1982 cost study in Pennsylvania found that the average annual salary of an institution worker was $14,161 compared to $9,304 earned by community residential program workers. 16/ Institution fringe benefits amounted to 36.4 percent of base salaries whereas fringe benefits in community facilities were 21 percent of salaries. The specialization of labor

---

16/ Longitudinal Study of the Court-Ordered Deinstitutionalization of Pennhurst Residents: Comparative Analysis of the Costs of Residential and Day Service* within Institutional and Community Settings. Human Services Research Institute, Boston, Mass., Dec. 15, 1983. p. 57.

in institutions and the medical focus of institution staff are major factors contributing to increased staff costs in institutions.

Current and proposed ICF/MR regulations require a more intensive level of care and habilitation and training than is generally found in non-ICF/MR facilities. The level of care in ICFs/MR has been questioned by a study that found the level of care required in an ICF/MR to be more than was needed for certain institutionalized persons who could benefit from a more independent residential setting where less costly services would be more appropriate. 17/

17/ U.S. Department of Health and Human Services. Placement Care of the Mentally Retarded: A Service Delivery Assessment. National Report to the Secretary, Office of the Inspector General. Oct. 1981.

VI. SELECTED ISSUES REGARDING THE EXPANSION OF COMMUNITY-BASED SERVICES

A. Increased Demand for Community-Based Services for MR/DD Persons

Several factors contribute to the demand for increased community residential services and community-based daytime services: the movement of MR/DD persons out of institutions, the movement of young MR/DD adults out of special education classes, and the increased demand for community-based services by MR/DD persons who have been maintained at hone and in non-medical board and care facilities.

Over the past 15 years, many MR/DD persons have been moved from care settings that fostered dependence and social segregation to settings that facilitate community integration and maximum independence. This philosophy is set forth in the Developmental Disabilities Act which is intended to promote independence, productivity, and integration into the community. The movement of MR/DD persons is facilitated by public and private efforts to develop group homes, daytime therapeutic programs, and employment opportunities. Daytime programs include day activity programs, in which productive work is not emphasized; sheltered employment, in which subminimum wages are paid in proportion to productivity; and supported employment, in which special supervision and assistance is provided to enable the disabled person to earn competitive wages. Experience has shown that many MR/DD persons who were previously institutionalized are capable of a degree of independent activity if the necessary training, supervision, and other assistance is provided. For example, many MR/DD persons who were previously determined to require institutional care are now living in small, supervised community-based residences, taking public transportation to sheltered or supported jobs, participating in community recreation activities, receiving social services where needed, and Leading semi-independent lives. If a crisis should occur, the individual may require intensive attention or retraining, or may require temporary institutionalization. However, if the philosophy of the Developmental Disabilities Act is being implemented, the individual would be offered opportunities to re-enter a more independent living and working life style after the crisis was resolved.

The mandate that States provide special education to all. handicapped children has generated rising expectation regarding the opportunities that will be available to these young people when they leave the school systems. Families accustomed to having educational and other support services available to their handicapped child see that with help, these persons are capable of some degree of independence and productivity. Therefore, as these young people leave school, their families arc advocating for increased availability of group homes, supported employment, and the array of intervention services required to maintain the progress experienced during the developmental period. Because the major source of funds for adult MR/DD persons is the Medicaid program, advocates for MR/DD persons are Looking increasingly to the Medicaid program to help support the array of services needed to sustain MR/DD persons in community-based settings. This raises a question about the appropriateness of the

Medicaid program as the funding source for certain of these community-based services, since Medicaid was originally intended to provide medical and medically-related services.

As discussed earlier, the number of MR/DD persons potentially eligible for ICF/MR services may be more than double the number currently receiving services. Persons being taken care by families or living in board and care facilities may not be getting the daytime habilitation services they need to progress into supported employment or other productive activity. If additional community-based services are made available, additional demand can be expected to arise on behalf of MR/DD persons.

The total number of MR/DD persons is affected by advances in medical care and life-saving devices, which nay be having a dual effect on the incidence of MR/DD persons. (Data are not available to show the numerical effects of these influences.) For example, intensive care for premature infants allows some newborns to survive who would have died in the past. However, some of these infants are left with severe disabilities that require life-long care and treatment. On the other hand, amniocentesis allows parents to know the disability status of their unborn children, and this may reduce the incidence of certain kinds of disabling conditions, because of termination of pregnancy.

B. Appropriate Settings for Residential Services for MR/DD Persons

There is considerable disparity of opinion regarding the type of service setting considered most appropriate. Some professionals, parents of disabled persons and other interested and informed persons, feel that family-style or individualized living arrangements provide a superior residential and service setting for the needs of all MR/DD persons by providing personalized care in a more normal, community-based setting. According to this position, large facilities are dehumanizing and degrading and are often the locations of flagrant abuse and neglect. Because these institutions tend to be isolated from normal community interactions and normal role models, disabled persons can become less able to function in normal community settings after entering an institution, according to this argument. Some families of institutionalized persons would prefer to have their disabled family member in a more normal community setting near the rest of the family.

On the other hand, some professionals, parents of disabled persons, and other knowledgeable persons, have stated that not all MR/DD persons can be adequately trained and cared for in the community. According to this position, there should be available a continuum of care, ranging from small family-scale residences to high quality institutions, to meet the diverse needs of the severely disabled population. It is argued that the critical factors determining quality of care are quality of staff, staff-client ratios, active family : involvement, and on-site health and therapeutic services, not the size or location of the residential facility. Some parents of institutionalized MR/DD persons feel that their family member is getting appropriate, effective care in an institution. These parents want the security that they feel they have in the institutional setting. Such parents want the assurance that their offspring will continue to receive care after the parents die. Some such parents fear that community services may become fragmented, may be discontinued, and nay not provide the total care provided in one setting by an institution.

Litigation and legislation have focused public attention on abuses and deficiencies in institutions for MR/DD persons. There is general agreement that ICF/MR regulations have been instrumental in significantly improving conditions in institutions, and there are many institutions that provide appropriate services in safe, humane environments. However, testimony, presented at congressional hearings held in 1985, showed that abuse and neglect continue to be serious problems at some institutions for MR/DD persons. 18/ Witnesses told of physical and sexual abuse by other residents and staff, verbal abuse, self-destructive behavior of residents due to neglect, excessive use of medication, excessive solitary confinement, inappropriate use of mechanical restraint, untreated injuries, filthy and foul-smelling facilities, and inadequate reporting and correction of abuse by institution staff and administrators. Such abuse and deficiencies have convinced some persons that institutions are unsuitable settings for services for MR/DD persons. On the other hand, persona who favor the option of larger residential facilities advocate improvement in the quality of care delivered in institutions and the correction of deficiencies in these facilities. As discussed earlier, administrative actions have been taken to address these problems. Also, legislation has been introduced to help improve conditions in institutions. Congressional hearings have not been held on possible abuses in community-based facilities, and published, systematic studies are not available on this issue.

Although empirical research on institutional versus community care is not conclusive, most studies tend to support the contention that community-based services conducted in as normal a setting as possible are more effective than institutional services in promoting developmental growth and independence of MR/DD persons. A move from institutional to community settings tends to result

---

18/ U.S. Congress. Senate. Committee on Labor and Human Resources. Subcommittee on the Handicapped. Abuse of Institutionalized Handicapped Persons. Hearings, Apr. 1, 2, and 3, 198S.

in positive social adjustment and improved behavioral development for many disabled persons. 19/ However, for developmental growth to take place, according to research findings, the community setting must include certain essential features: effective teaching techniques, friendship networks for disabled persons and active involvement and positive attitudes of care providers. Some research has found that large institutions in which these features are present are also effective settings for developmental growth and that reducing the size of a facility does not necessarily change the daily pattern of care. 20/

Research indicates that there is great variation in community residential facilities. To provide as normal an environment as possible, community facilities need to be enriched with various therapeutic and rehabilitative programming. Studies have shown that clients in community care facilities benefit from increased interaction with qualified care providers within the community facility and from involvement in community activities and services outside the facility.

C. Service Settings and Costs of Residential Services for MR/DD Persons

Over the past 15 years, as MR/DD persons have been moving out of large public institutions into smaller private facilities, group hones or other community-based Living arrangements, the cost of the ICF/MR program has been increasing.

19/ Conroy, James, et. al. A Hatched Comparison of the Developmental Growth of Institutionalized and Deinstitutionalized Mentally Retarded Clients. American Journal of Mental Deficiency, v. 86, no. 6, 1982. p. 581-587.

20/ Selzer, Marsha, Ph.D. Known Effects of Environmental Characteristics on Resident Performance, LINKS, Bed. 1981.

Although the numbers of MR/DD persons served in public residential institutions decreased 42 percent between FY 1970 and FY 1984, from 189,546 to 109,827, the total number of residents in ICFs/MR rose steadily from the beginning of the ICF/MR program in 1972 until FY 1981 when the ICF/MR population peaked at 173,764. By FY 1984, the ICF/MR population had decreased 9 percent since the peak year, but the total Federal ICF/MR reimbursement increased by 40 percent from FY 1981 to FY 1984. However, part of this increase was due to changes in the cost of living, which increased 15.7 percent between FY 1981 and FY 1984. The average Federal ICF/MR per capita expenditure in FY 1981 was $10,553; this expenditure increased to $16,217 in FY 1984. 21/ (The average total ICF/MR per capita expenditure in FY 1984, State plus Federal, was $30,598.)

This increase in ICF/MR costs may be due to the increased expenditures required to bring facilities into compliance with standards and to the overhead required to maintain a large, comprehensive service facility. Even if the client population declines, staff of a large institution cannot be expected to decline proportionately because division of labor in a multi-service facility requires a large and diverse number of staff. Expenditures required to bring the facility into compliance with ICF/MR standards are prorated over time, and cannot be expected to decrease unless parts of the facility are sold, leased, or converted to another use. Therefore, even though MR/DD persons are increasingly placed in small, less expensive service settings, savings are difficult to obtain while the large, comprehensive institutions continue to be maintained.

21/ These expenditures are based on data presented in table 3.

Advocates for small, community-based facilities have stated that there is not sufficient public funding available for the expansion of community-based facilities while the large institutions absorb the major share of funds. This dilemma has led to legislative proposals requiring that public funding be reduced in large institutions and be made available in small, community-based facilities.

Although data show that public facilities are more costly than smaller, privately-operated facilities (see table 4), if staff salaries and benefits in private facilities were brought up to levels of State employees, this difference would be reduced. Also, if services were made more broadly available in the community, increased demand by persons not currently served could lead to increased overall costs. One mitigating factor, however, is that it could be less costly to provide community services to MR/DD persons who do not need the level of care provided in ICFs/MR. That is, some persons currently getting no community services may request some, but not all, of the services now made available in the ICFs/MR. Also, some residents of ICFs/MR nay require fewer services than arc required to be provided within the ICF/MR.

VII. LEGISLATIVE PROPOSALS

A. S.873: The Community and Family Living Amendments of 1985

S. 873, introduced by Senator Chafee, would make Federal funds available in small community facilities while phasing out most Federal funding for institutions of more than 15 beds. Companion bills have been introduced in the House: H.R. 2523, introduced by Representative McDade, which is identical to S. 873, and H.R, 2902, introduced by Representative Florio, which includes minor differences.

These bills would encourage the development of community-based services for severely disabled individuals, and would severely reduce the amount of ICF/MR expenditures to be used for services in institutions after FY 2000. The balance of ICF/MR funding, with limited exceptions, could only be used for severely disabled individuals who resided in a family home or community living facility. Community living facilities could not exceed three times average family household sire, or approximately nine persons. States would enter into agreements with the Secretary of HHS to reduce the number of disabled persons residing in facilities of more than nine beds. Beginning in FY 2000, the amount of Federal funding available for use in larger residential facilities would be limited to approximately 15 percent of the amount currently used. In addition, beginning in FY89, the Federal matching rate for services delivered in larger facilities would be progressively reduced.

The amendments would allow facilities of no more than 15 beds to continue to receive funding if they were in operation on September 30, 1985.

B. S. 1277 and H.R. 2863; Proposed Medicaid Hone and Community-Baaed Services Improvement Act of 1985

S. 1277, introduced by Senator Bradley and H.R. 2863, introduced by Representative Wyden are identical bills that would give States the option of providing home and community-based services under Medicaid. This legislation would eliminate the current requirement that States obtain a waiver from the Secretary to deliver such services using Medicaid funds. Under this proposal, States would be authorized to deliver home and community-based services to persons who would otherwise require care in skilled nursing facilities and intermediate care facilities, the cost of which would be reimbursed under the State Medicaid plan. This could include aged persons and persons with mental illness, mental retardation or physical disabilities who are eligible for Medicaid services.

C. S. 1948: Proposed Quality Services for Disabled Individuals Act of 1985

S. 1948, introduced by Senator Weicker, is intended to improve the quality of residential services for persons with developmental disabilities or mental illness and to authorize home and community-based services under the Medicaid program. This bill would establish a new Federal bureau to administer residential and community-based services funded under Medicare and Medicaid and to monitor the quality of these services.

A major provision of S. 1948 is that States would be required to include home and community-based services for the developmentally disabled as part of their State plan for use of Medicaid funds. Currently, such services are available only under the special waiver authority granted to the Secretary. Home and community-based services would be defined to include case management, homemaker or home health aide services, personal care including attendant care, adult day health services, habilitative and rehabilitative services, respite care (short-term residential care), and other approved services excluding room and board. States providing home and community-based services under Medicaid would be required to maintain at least their fiscal year 1985 level of State funding for such services, and current waiver authority would be repealed.

APPENDIX A. GLOSSARY OP TERMS

Adult day care consists of a variety of health and social services provided to chronically ill or disabled individuals in a group setting and often includes general nursing, personal hygiene, recreational activities, counseling, transportation, and nutrition services.

Case Management is commonly understood to be a system under which responsibility for locating, coordinating and monitoring a group of services for chronically ill or disabled persons rests with a designated person or organization.

Habilitation services are typically health and social services needed to insure optional functioning in activities of daily living of the mentally retarded or persons with related conditions.

Home health aide services include health-related services provided by a trained paraprofessional to persons unable to manage care for themselves or others in the home. Services generally consist of extension of therapy services, ambulation and exercise, assistance with medications, reporting changes in the patient's condition and needs and household services essential to the health care at home. These services are generally provided under the supervision of a registered nurse.

Homemaker services typically consist of general household activities (meal preparation and routine household care) provided by a trained homemaker when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for himself/herself or others in the home.

Personal care services are those that assist functionally limited individuals with bathing, eating, dressing, toileting (generally referred to as "activities of daily living").

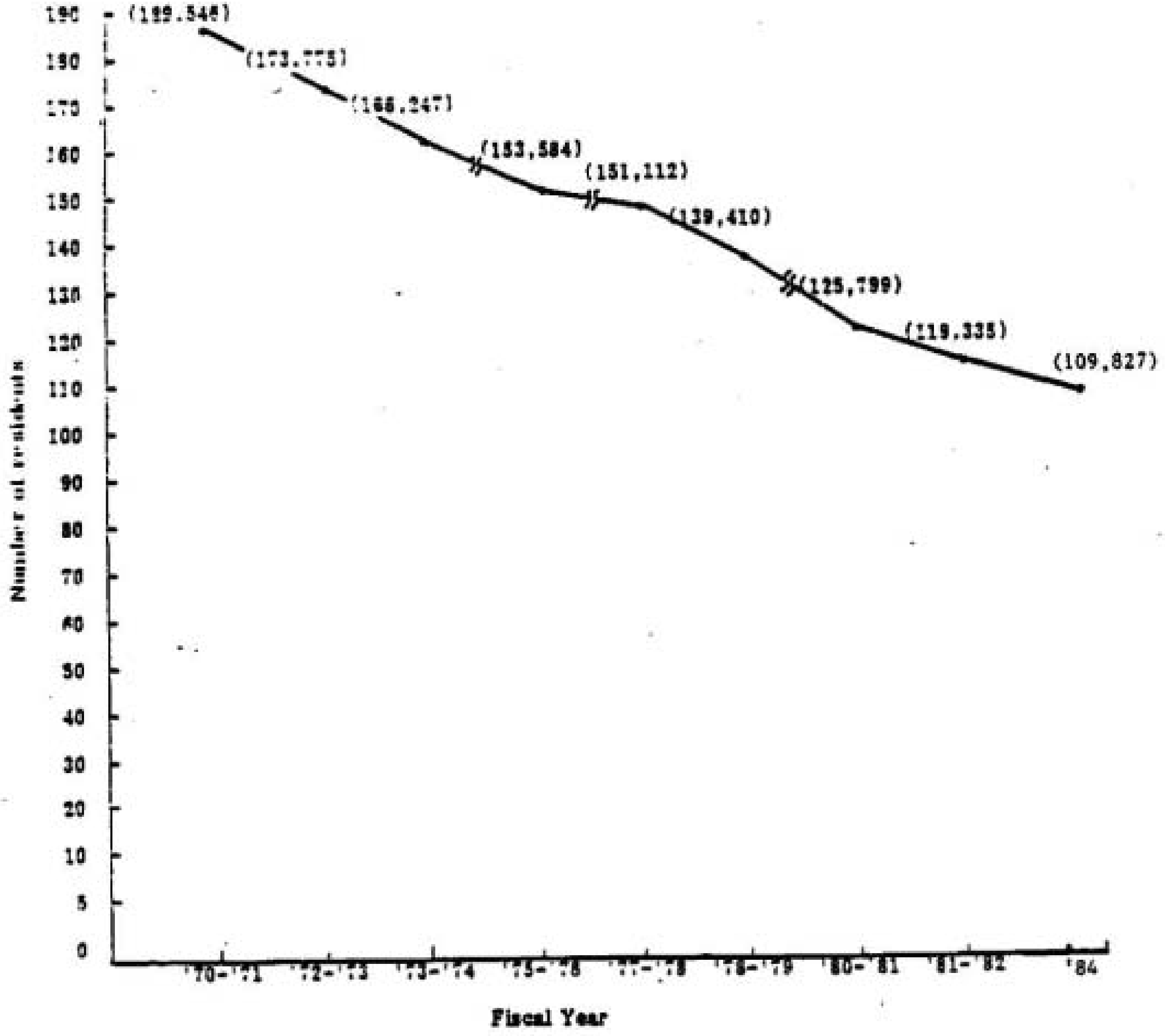
Prevocational services are those services needed to develop basic work habits and personal skills required for a disabled individual to take advantage of vocational rehabilitation services.

Respite care is short term care provided to individuals unable to care for themselves in order to provide relief for family or other persons normally providing the care. Respite care services may be provided in the individual's home or in an approved facility, such as a hospital, nursing home, foster home, or community residential facility.

Supported employment is competitive work in a setting with nondisabled persons for individuals with severe disabilities who require special supervision and assistance to perform the duties of the job.

Vocational rehabilitation services are provided to disabled persons to help make such persons employable. Services include physical, and mental restoration, vocational training, special devices required for employment, job placement, and follow-up services.

APPENDIX B. AVERAGE DAILY POPULATION OF MENTALLY RETARDED PERSONS IN PUBLIC RESIDENTIAL FACILITIES: FY 1970-FY1984



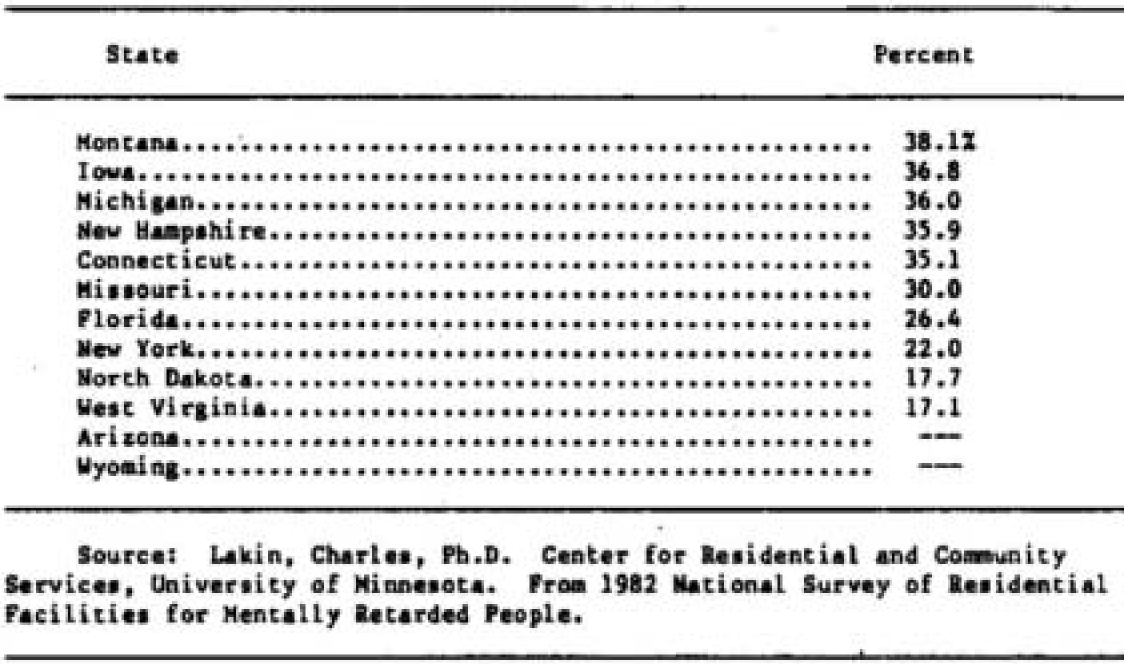
Source: Table taken from Public Residential Facilities for the Mentally Retarded. 1982. Published by National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. p. 4.

The 1984 number is from Public Expenditures for Mental Retardation and Developmental Disabilities in the D.S., Analytical Summary, by David Braddock, Ph.D., et al. University of Illinois at Chicago. p. 15.

APPENDIX C. PERCENT OF TOTAL PUBLIC AND PRIVATE RESIDENTIAL CARE FOR THE MENTALLY RETARDED IN MEDICAID-CERTIFIED ICF/MR BEDS, BY STATE: FY82

State	Percent
Minnesota	98.1%
Louisiana	95.9
Utah	88.8
Texas	88.6
Rhode Island	87.1
Virginia	85.1
Arkansas	83.8
Oregon	77.3
Alabama	75.6
Colorado	75.3
South Carolina	73.2
Georgia	72.8
Washington	72.3
Kansas	72.3
Indiana	70.6
Tennessee	67.4
Kentucky	67.2
Delaware	67.1
New Mexico	65.4
Illinois	64.0
North Carolina	63.0
Wisconsin	62.4
Nebraska	60.4
Mississippi	60.3
Oklahoma	59.9
South Dakota	59.3
Massachusetts	59.1
Nevada	58.1
Maryland	57.0
Idaho	56.0
Ohio	55.6
Pennsylvania	55.2
New Jersey	50.0
District of Columbia	49.2
Vermont	48.2
Alaska	47.6
Hawaii	45.2
California	44.8
Maine	43.0

APPENDIX C. PERCENT OF TOTAL PUBLIC AND PRIVATE RESIDENTIAL CARE SYSTEM FOR THE MENTALLY RETARDED IN MEDICAID-CERTIFIED ICF/MR BEDS, BY STATE: FY82—Continued



State	Percent
Montana	38.1%
Iowa	36.8
Michigan	36.0
New Hampshire	35.9
Connecticut	35.1
Missouri	30.0
Florida	26.4
New York	22.0
North Dakota	17.7
West Virginia	17.1
Arizona	---
Wyoming	---

Source: Lakin, Charles, Ph.D. Center for Residential and Community Services, University of Minnesota. From 1982 National Survey of Residential Facilities for Mentally Retarded People.

APPENDIX D: AVERAGE MEDICAID PAYMENT PER PATIENT DAY FOR ICF/MR SERVICES RANKED BY FY85 RATES

State	Per diem
District of Columbia	$145
Nevada	132
Massachusetts	126
Rhode Island	114
North Carolina	110
Georgia	107
Vermont	104
Florida	102
Pennsylvania	100
Maryland	99
Maine	98
Missouri	97
Kentucky	94
New Mexico	90
Arkansas	89
Iowa	89
Idaho	86
Colorado	85
Virginia	83
Nebraska	78
Oregon	78
Illinois	77
Tennessee	73
Minnesota	72
Ohio	70
Louisiana	68
South Dakota	64
Wisconsin	61
Michigan	52
Mississippi	49

APPENDIX D: AVERAGE MEDICAID PAYMENT PER PATIENT DAY FOR ICF/MR SERVICES RANKED BY FY85 RATES—Continued

State	Per diem
California	$48
Texas	48
Indiana	44
West Virginia	41
Kansas	40
Oklahoma	40

Source: Health Care Financing Administration. Division of Medicaid Cost Estimates. Medicaid Program Characteristics Data. 1986. States not included in this table did not report data in time for inclusion in this table or did not participate in the ICF/MR program.