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RESIDENTIAL AND COMMUNITY SERVICES FOR PERSONS WITH
MENTAL RETARDATION AND RELATED DISABILITIES:
BACKGROUND INFORMATION AND PROPOSED LEGISLATION

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ABSTRACT

Since 1973, Federal Medicaid funds have been used to help support services for institutionalized mentally retarded persons. Legislation has been introduced in the 99th Congress that would transfer most of these funds out of the institutions and make this funding available for community-based services. Advocates of the legislation believe that community-based services are preferable to institutional services, but some parents of institutionalized persons feel that the larger residential facilities are a necessary part of the service system.

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INTRODUCTION

For the past 20 years there has been considerable concern about the quality of care in some of the large residential institutions that provide care for persons with mental retardation and related disabilities. The term institution generally refers to a residential facility of several hundred beds or more that provides 24-hour care, seven days a week. The Federal Government helps support services in those institutions that meet, or have a plan to meet, Federal standards of care. However, recent judicial actions and legislative hearings indicate that abuses and other problems remain in some institutions.

Over the past 15 years there has been a steady decline in the number of persons served in 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. Legislation was introduced in the 98th and 99th Congresses to strengthen the community care system and to make more Federal funding available for increased community services. This legislation would decrease the amount of Federal funding that could be used in institutions and make these funds available for community services for persons residing in small community residences or family homes. This legislation is supported by individuals who believe that community care is

preferable for virtually all clients. It is opposed by those persons who believe that, while community care is appropriate for many handicapped persons, some require institutional care.

BACKGROUND

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 institution 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 characterizes 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/

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

/ 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.

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. 2] 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.

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 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. 3/

2/ The President's Panel on Mental Retardation. A Proposed Program for National Action to Combat Mental Retardation. Report to the President, Oct. 1962.

3/ For additional background INFORMATION see, Paul, James, L., Donald 3 Stedman, and G. Ronald Neufeld, eds. Deinstitutionalization: Programs and Policy Development. Syracuse, University Press, 1977.

I. RESIDENTIAL FACILITIES FOR MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PERSONS (MR/DD): DATA SUMMARY 4/

A 1982 survey indicated that in that year there were 243,669 retarded persons served in some type of facility specifically licensed for the care of mentally retarded people: public or private institutions, nursing homes, supervised group or individual living arrangement, foster care, and boarding homes. (This number does not include disabled persons living with their families or

TABLE 1. Number of Persons with Mental Retardation or Related Conditions Served in State Licensed Residential Facility as of June 30, 1982

Number of beds in facility	Number of persons served	Number of facilities
a/		
1-6	33,188	1,469
7-15	30,515	3,39
16-63	25,691	1,09
64-299	45,709	495
300+	<u>108,566</u>	<u>178</u>
Total	243,669	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)).

4/ The term mentally retarded and other developmentally disabled persons, a term commonly used in the field, is used in this paper to generally encompass
(continued)

living in non-licensed facilities.) Table 1 shows the number of persons served by size of facility and the number of facilities in each size category.

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 persons are in operated facilities of over 300 beds.

Over the past decade there has been a nationwide effort to move the less severely disabled persons out of large public institutions and into small community-based facilities. As a result of this effort, the population of public institutions decreased 42 percent between 1970 and 1984, from 189,546 to 109,827. 5/ Since 1977, 19 State institutions have closed and five are in the process of closing.

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

(continued) persons with severe, life-long impairments, usually including mental retardation. The Medicaid program, authorized under title XIX of the Social Security Act, provides Federal funds to help support services for "mentally retarded or persons with related conditions" who require institutional care. Related conditions generally include neurological impairments such as cerebral palsy, epilepsy or autism. Persons with these impairments generally require multiple services over an extended period of time.

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

retarded. Those remaining in institutions are also now more likely to have multiple handicaps. Of the institutionalized retarded persons: 12 percent are also blind; six percent are deaf; 41 percent have epilepsy; 21 percent have cerebral palsy; and 36 percent have 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 cannot walk without assistance;
- 61 percent cannot dress without assistance;
- 40 percent cannot eat without assistance;
 - 28 percent cannot understand the spoken word;
- 55 percent cannot communicate verbally; and
- 40 percent are not toilet-trained.

In 1982, 21 percent of the MR/DD persons in public institutions were under age 22, 74 percent were ages 22 to 62, and five percent were over age 62.

Although total institution populations decreased 21 percent between 1976 and 1982, there was a 15 percent increase in the institutionalized population age 22 or older. This indicates a decrease in the admissions of MR/DD children to institutions. Services provided under the Education for All Handicapped Children Act are generally considered the major reason for the decrease in the number of MR/DD persons under age 22 who have been institutionalized since 1976.

As MR/DD persons have moved from institutions to community-based group homes, the number of such homes has increased substantially. A telephone survey conducted in the spring of 1982 indicated that there were 6,302 group homes

for persons with mental retardation, 91 percent of which had 15 beds or less.

The group homes served a total of 57,494 persons, with an average of 9.12 persons in each group home. Group homes of 15 beds or fewer housed an average of 7.38 persons per site. The number of community living facilities of 15 beds or less increased over 900 percent between 1972 and 1982. 6/

II. FEDERAL PROGRAMS FOR INSTITUTIONALIZED MR/DD PERSONS

Federal funds to help support services for institutionalized MR/DD persons are authorized under the Medicaid program, title XIX of the Social Security Act. The MR/DD population requiring 24-hour care may receive such services in several types of federally funded institutional settings. To receive Federal funds, these facilities must meet certification standards established under the Medicaid program. There are three types of Medicaid-certified facilities in which MR/DD persons are provided care: intermediate care facilities for the mentally retarded and persons with related conditions (ICFs/MR), intermediate care facilities (ICFs) and skilled nursing facilities (SNFs).

1. Most institutionalized MR/DD persons receive services funded in part by the ICF/MR program, a service authorized in 1971 to be included, at State option, in a State's Medicaid plan. An institution is eligible for ICF/MR payments if the primary purpose of such institution is to provide health or rehabilitative services for mentally retarded individuals and if the facility meets Federal standards. Institutionalized persons for whom payment is made must receive active treatment under the program. In FY84, approximately 139,000 MR/DD persons were residents of a Medicaid-certified ICF/MR. These facilities range in size from four to 2,000 beds, but the great majority of these residents, over 90 percent, are in facilities of 16 beds or more. Facilities with under 200 beds are largely administered by the private sector, and those over 200 beds are usually public institutions. Federal

/ Janicki, M. P., et. al. Availability of Group Homes for Persons with .Mental Retardation in the United States. Mental Retardation, v. 21, no. 2, April 1983. p. 48-50.

regulations providing standards for ICFs/MR are intended to assure a safe and therapeutic environment and include provisions for adequate staffing, health and safety requirements and minimum specifications for individual space and privacy. 7/ An individual plan of care is required for each resident. The plan must include services necessary to enable residents to attain or maintain optimal physical, intellectual, and social and vocational functioning. States vary considerably in the proportion of total public and private residential care beds that are ICF/MR certified, ranging from 98 percent in Minnesota to zero in Arizona and Wyoming. 8/

2. Some MR/DD persons are served in nursing care homes certified under Medicaid as ICFs. These facilities provide health-related care and are not required to provide the habilitation services authorized in the ICF/MR program. HCFA has issued a statement saying that the acceptance of MR/DD persons in ICFs and SNFs is generally inappropriate, but service needs of such persons currently in such facilities are to be met. Approximately 30,000 MR/DD persons are currently served in ICFs, according to an unofficial estimate of the Congressional Budget Office (CBO). 9/
3. The SNFs serve some MR/DD persons who require a greater degree of health care than is provided in ICFs. Approximately 13,500 MR/DD persons are served in SNFs, according to the CBO memorandum.

The three services mentioned above are funded through open-ended entitlements for eligible persons. That is, States are not limited in the amount of Federal funds they may receive for services provided to eligible individuals as long as they meet standards and provide the required matching funds. The ICFs and ICFs/MR may be included in Medicaid State plans; SNFs are required to be included for eligible persons over age 21. The Federal share for these services ranges from 50 to 83 percent of total costs of services depending on the State per capita income. The average Federal share for these services is currently 53 percent.

7/ 42 C.F.R. 442 subpart G, promulgated in 1974.

8/ See appendix B. Arizona does not have a Medicaid program. Wyoming does not cover ICF/MR services in its State Medicaid plan.

9/ U.S. Congressional Budget Office. Memorandum to Christine Ferguson of Senator John Chafee's staff from Diane Burnside of CBO, Dec. 12, 1983. The data in this memorandum are preliminary staff estimates and are not to be considered official CBO estimates.

Of the approximately 244,000 MR/DD persons in State-licensed public and private residential facilities on June 30, 1982, about 58 percent were receiving Medicaid-supported services. The remainder were in foster care, group homes and public and private institutions which are supported primarily by State and Federal income maintenance support paid to MR/DD persons, as well as with State funds, private donations, and fees paid by families.

III. OVERVIEW OF RECENT REGULATORY, JUDICIAL AND LEGISLATIVE ACTIONS TO REDUCE ABUSES OF INSTITUTIONALIZED MR/DD PERSONS

Litigation and legislation have focused public attention on abuses and deficiencies in institutions. There is general agreement, however, that ICF/MR regulations published in 1974 have been instrumental in significantly improving conditions in institutions. According to many experts in the field, there are many institutions which provide appropriate services in safe, humane environments. The following discussion is not intended to imply that abuses exist in all institutions.

A. Examples of Institutional Abuse

In the spring of 1985, congressional hearings were held on abuse of institutionalized handicapped persons. 10/ Testimony presented at that time showed that abuse and neglect continue to be serious problems at many institutions. Witnesses told of physical and sexual abuse by other clients and by staff, verbal abuse, self-destructive behavior of clients due to neglect, excessive use of medication, excessive solitary confinement, inappropriate use of mechanical

10/ U.S. Congress. Senate. Committee on Labor and Human Resources. Subcommittee on the Handicapped. Abuse of Institutionalized Handicapped Persons. Hearings, April 1, 2, and 3, 1985.

restraint, untreated injuries including broken bones, lack of personal privacy and personal belongings, facilities that were filthy and foul-smelling, and inadequate reporting and correction of abuse by institution staff and administrators.

B. Intermediate Care Facilities for the Mentally Retarded (ICF/HR) Standards

The promulgation of ICF/MR regulations in 1974 was an effort to establish and ensure active treatment and a safe environment in institutions for MR/DD persons. However not all beds in all institutions have qualified for ICF/MR certification, and those programs which have been certified may not always conform to all provisions of the ICF/MR standards. Eighty-seven percent of the residents of public institutions are in certified beds, and most States have certified all State institution beds. 11/ Most of the non-certified beds are in 10 to 12 States. Beds in institutions can be certified even if they do not meet all ICF/MR standards if there is a plan of correction to bring the beds up to standards. The certification process is not supposed to allow repeat deficiencies, but most of the reported abuses have generally been known for some time. 12/

States have the responsibility to determine whether a facility is eligible for Medicaid certification and is meeting ICF/MR standards. If facilities are found out of compliance, Medicaid funds can be disallowed or deferred until the

11/ Lakin, Charles, Ph.D. Center for Residential and Community Services, University of Minnesota. Telephone conversation with the author. Dec. 3, 1984. Data from 1982 National Census of Residential Facilities.

12/ Ibid.

facility is brought into compliance. In addition to funding penalties, legal action can be initiated.

C. Litigation and State Actions

Numerous court cases have reported various physical and psychological abuses which have taken place and continue to take place in some institutions for MR/DD persons. There are currently dozens of such court cases. For example, in Youngberg v. Romeo, 457 U.S. 307 (1982), the plaintiff had been injured over 70 times while a resident in a State institution. In this case, the Supreme Court found that institutionalized mentally retarded persons have the right to adequate food, clothes, shelter and medical care, the right to personal safety, the right to freedom from unnecessary physical restraint, and the right to training necessary to further their interest in safety and freedom from undue restraint.^{13/} However, the Supreme Court did not address the issue of a right to treatment or developmental training.

D. Civil Rights Statute

In 1980, the Civil Rights of Institutionalized Persons Act (CRIPA), 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 or practice of denial, if the suit

^{13/} Other major cases include Wyatt v. Stickney, 344 F. Supp. (M.D. Ala., 1972), affirmed in part, remanded in part, and reserved in part, sub nom., Wyatt v. Aderhalt, 503 F. 2d 1305 (5th Cir., 1974) and Pennhurst State School and Hospital v. Halderman, 451 U.S. 1 (1981), and 465 U.S. —, 1045 Ct. 900, 79 L. Ed. 67, 52 U.S. L.W. 4155 (1984).

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. Since the enactment of this statute, the Attorney General has undertaken 57 investigations of institutions, 12 of which involved mental retardation facilities. 14/ However, the Department has not actively litigated any mental disability cases under CRIPA and has initiated only one case. 15/

IV. COMMUNITY-BASED SERVICES UNDER THE MEDICAID WAIVER

In an effort to increase home and community-based services to persons who are institutionalized or at risk of being institutionalized, title XIX was amended in 1981 to allow the use of Medicaid funds for a broad range of home and community-based services. 16/ The following groups may be served under the waiver program: the aged, the physically disabled, the mentally retarded, and the mentally ill. The waiver program, authorized under section 1915(c) of the Social Security Act, provides that Federal Medicaid funds may be used to support home or community-based services (other than room and board) for persons who, but for the provision of such services, would require the level of care provided in Medicaid-supported institutions.

14/ U.S. Department of Justice. Special Litigation Section. Civil Rights Division. Conversation with Ben Schoen by the author. June 27, 1985.

15/ Dinerstein, Robert D. The Absence of Justice, 63 Neb. L. Rev. 680, 703 (1984).

16/ Title XIX was amended by P.L. 97-35 (sec 2176). This provision allows the Secretary of the Department of Health and Human Services (DHHS) to waive certain requirements only available in institutions such as the availability of emergency care on the premises, and the requirement that services be delivered Statewide.

States must set forth a number of assurances to qualify for the waiver:

- Safeguards are required to protect the health and safety of persons provided services and to assure fiscal accountability for the funds expended.
- Persons entitled to institutional services are to be evaluated to determine the need for such services.
- Persons determined to be likely to require institutionalization are to be informed of the alternative available under the waiver program.
- The average per capita Medicaid expenditure for services under the waiver is not to exceed the average per capita Medicaid expenditure that the State would have made if the waiver had not been granted, i.e., the cost of community services is not to exceed the cost of institutional services.
- States are to provide annual reports on the impact of the waiver program which include data on the types and amount of assistance provided and information on the health and welfare of the recipients.

Services authorized under the waiver provision include case management services, homemaker and home health services, personal care services (such as bathing and toileting), adult day health care, habilitation services to provide training in the activities of daily living, respite care for families, and other services as approved by the Secretary of DHHS.

A State may be granted a waiver for three years initially and the waiver may be extended for additional three-year periods unless noncompliance with the provisions of the waiver is determined. As of May 31, 1985, 42 waivers had been granted for programs serving MR/DD individuals in 36 States. It is estimated that 17,000 MR/DD persons had received community services under the waiver provisions as of June 1, 1984. Over half of these persons were served in three States: Florida, Louisiana and Oregon.

The costs of the total Federal share of services furnished under the waiver provisions to the aged and the disabled have increased rapidly: \$2.1 million in FY82, \$47 million in FY83, \$104.1 million in FY84, and \$191.6 million for the

first quarter of FY85. It is estimated that the Federal share of costs incurred under the waiver provision will exceed \$800 million in FY85. 17/ It is not known what proportion of the expenditures incurred under the waiver was used for services for the MR/DD population, but it is estimated that approximately one-third of the clients were MR/DD persons, and possibly one-half of the cost was for MR/DD clients. (Estimate provided by an official of the National Association of Coordinators of State Mental Retardation Program Directors.)

The final regulation for the waiver program was published on March 13, 1985 (50 Federal Register 10013). As required by statute, the regulation requires States to provide assurances that the average per capita fiscal year expenditure under the waiver will not exceed the average per capita cost had the individual been institutionalized. Under the regulation, States must also assure that the actual total cost of home and community-based services under the waiver will not exceed the State's approved estimate for such services. States must also assure that total costs under the waiver will not exceed the total Medicaid costs that would have been incurred if the disabled persons served under the waiver were served in ICF/MR-certified institutions. The preamble to the regulation states that the services to be assessed in the comparison of total costs are to include physician services, acute hospital care, dental care and prescription medication, as well as the types of home and community-based services listed above. The final regulation specifically prohibits States from offering prevocational or vocational training under the waiver program.

The waiver program is intended to enable persons to leave institutions and to provide an alternative for those at risk of entering an institution. The regulation requires States to specify the number of each type of client, and to

17/ These data were provided by officials of the Health Care Financing Administration.

assure that services furnished under the waiver are limited to persons who would otherwise receive institutional care. 18/

V. COST SUMMARY: FUNDS USED FOR RESIDENTIAL SERVICES
FOR THE MR/DD POPULATION

A. Distribution of Public Funds

A report by the Office of the Inspector General of DHHS estimated that for FY81, public spending for both residential and support services for the mentally retarded population was \$11.7 billion. 19/ Table 2 shows that the Federal portion was estimated to be \$5.4 billion and the State portion was estimated to be \$6.3 billion. Approximately half (\$5.9 billion) of the public funds were spent on residential care. This report estimates that at least \$4.5 billion was spent on community-based support services which ranged from medical care to special education. It was estimated that about \$1.3 billion in supplemental security income (SSI) and social security disability insurance (SSDI) payments were made to, or on behalf of, individuals living in the community.

^{18/} For additional information, see U.S. Library of Congress. Congressional Research Service. Medicaid "2176" Waivers for Home and Community-Based Care, Typed Report No. 85-817 EPW, by Carol O'Shaughnessy and Richard Price, June 21, 1985. Washington, 1985.

^{19/} U.S. Department of Health and Human Services. Office of the Inspector General. Placement Care of the Mentally Retarded: A Service Delivery Assessment. National Report to the Secretary. Washington, Oct. 1981. p. 11.

TABLE 2. Public Funds for Mentally Retarded Persons: FY81
(in billions of dollars)

Fund allocations	Amount allocated
TOTAL funding	\$11.7
<u>Source of funds:</u>	
1. Federal	(\$5.4)
2. State.....	(\$6.3)
<u>Expenditures:</u>	
1. Residential care	\$ 5.9
-Institutions	(\$3.7)
-Community facilities	(\$0.7)
-Other long-term care	(\$1.1)
-Miscellaneous	(\$0.4)
2. Community-based support services.....	\$ 4.5
3. SSI/SSDI and State grants to counties.....	\$ 1.3

B. Trends in Financing Institution and Community Services
for the MR/DD Population

A recent study analyzed total public expenditures for the MR/DD population receiving services in State-operated institutions and in community facilities, most of which are privately operated. 20/ State-operated institutions are usually over 300 beds, whereas community facilities include small residences as well as larger privately-operated facilities, which may have over 100 beds. The study analyzed data beginning with expenditures for FY77 and made projections

20/ The data in this section are taken from Public Expenditures for Mental Retardation and Developmental Disabilities in the United States. Analytical Summary, Public Policy Monograph No. 6, by David Braddock, Ph.D., et al, Mar. 1985, published by the University of Illinois at Chicago.

for FY84. 21/ This analysis focused primarily on State general revenue expenditures and Federal ICF/MR reimbursements. The analysis did not include SSDI or SSI payments to individuals that were used for room and board in community facilities. The term adjusted for inflation as used in this discussion means that dollars in subsequent years are expressed in terms of their FY77 value.

1. Institution Expenditures

The study found that during this eight-year period, the total of State plus Federal expenditures for services in institutions did not increase, if data are adjusted for inflation. In fact, the total funding for FY84 was projected to be 0.8 percent less than expenditures for FY77, when adjustments are made for inflation. In unadjusted dollars, expenditures totalled \$2.436 billion in FY77 and were projected to increase to \$4.278 billion in FY84, according to this study.

The major change that occurred was that Federal funds were increasingly used to support institutional services as inflation increased. During this eight-year period, the Federal proportion of funds for services in institutions increased from 26 percent in FY77 to 46 percent in FY84. This resulted in a decrease in the State proportion from 74 percent in FY77 to 54 percent in FY84.

Although the total of State plus Federal expenditures did not increase over the period of the study, when figures are adjusted for inflation, Federal ICF/MR program funds increased an average of 10 percent per year as States

21/ See appendix C for a chart showing State and Federal expenditures in FY77 and in FY84.

received ICF/MR certification for institution beds that had previously been 100 percent State supported.

Although the institutionalized population of MR/DD persons decreased over the eight-year period, the daily cost of services for each person who remained in institutions increased. As the population of institutionalized MR/DD persons decreased 4.3 percent per year between FY77 and FY84, per diem expenditures for the persons residing in institutions increased 4.5 percent annually, if data are adjusted for inflation. The institutionalized population was more severely impaired and in need of more intensive services in FY84 than in FY77 because many of the less severely disabled persons were moved from the institution to the community during that period.

2. Community Expenditures

Funding for community residential and support services for the MR/DD population increased over the eight-year period from \$745 million in FY77 to \$3.1 billion in FY84, in unadjusted dollars. This funding increased at an annual rate of 22.8 percent per year in unadjusted terms, or 13.4 percent in adjusted terms. 22/ Seventy percent of the funds used to develop community services over this time period was contributed by the States; this percentage remained constant each year. Federal ICF/MR funding in community facilities increased from six percent of total expenditures in FY77 to 21 percent in FY81. Federal funds for social services authorized under title XX of the Social Security Act have been used to support community services for the MR/DD population. These funds decreased from 20 percent of total community expenditures in FY77 to seven percent in FY84.

22/ The 13.4 percent figure was calculated by the Congressional Research Service.

These calculations do not include Federal or State income maintenance payments made to individuals and used for room and board in community facilities. Persons determined to be disabled under title II (SSDI) or title XVI (SSI) of the Social Security Act are entitled to cash payments; these payments are not included in this determination of community expenditures.

C. Program Costs and Persons Served in the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) Program

Table 3 shows total ICF/MR expenditures and the Federal share of such expenditures since the inception of the program in FY73 through the estimated amount for FY85. ^{23/} The number of persons served is also shown. Currently about 80 percent of ICF/MR funds are used in public residential facilities and 20 percent of the funds are used in private residential facilities.

^{3/} The funds shown as total ICF/MR expenditures in table 3 include only those State funds required to match Federal ICF/MR funds, and do not include other State funds which have been used in residential facilities that are not ICF/MR certified.

TABLE 3. Total and Federal ICF/MR Expenditures and Number of Persons Served: FY 1973-FY 1985

Fiscal years	Total (in millions)	Federal (in millions)	Persons served (in thousands)
1973	\$ 165	\$ 98	29
1974	203	120	39
1975	380	204	69
1976	635	349	89
1977	917	501	107
1978	1,192	662	104
1979	1,488	823	114
1980	1,989	1,052	121
1981	2,996	1,742	151
1982	3,467	1,863	149
1983	4,079	2,122	151
1984	4,179	2,227	139
1985 (est.)	4,866	2,679	N/A

Source: Howe, Chris. Medicaid Statistics Branch. Medicaid Cost Estimates. Health Care Financing Administration. Mulligan, Bill. Division of State Agency Financial Management. Bureau of Program Operations. Health Care Financing Administration. Data obtained by telephone, June 21, 1985.

D. Per Diem Costs by Type of Facility

Numerous studies have attempted to identify the per diem cost differential between institution and community-based programs for the MR/DD population. A recent assessment of 11 of these studies shows that while there were lower average per diem 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. 24/

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 diem cost of a State-operated ICF/MR averaged \$87 in 1982, and ranged from a high of \$195 per day in Alaska to a low of \$28 per day in Kansas. 25/ The cost of a 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.

24/ 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.

25/ See appendix D for ICF/MR per diem rates by State.

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
<u>16+ beds</u>		
ICF/MR certified.....	\$87	\$51
Non-certified.....	73	39
<u>1-15 beds</u>		
ICF/MR certified.....	\$82	\$62
Non-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 salary of an institution worker was \$14,161 compared to \$9,304 earned by community residential program workers. 26/ Institution fringe benefits amounted to 36.4 percent of base salary whereas fringe benefits in community facilities were 21 percent of salaries. The specialization of labor in institutions and the medical focus of institution staff are major factors contributing to increased staff costs in institutions.

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

The ICF/MR regulations require a more intensive level of care and habilitation and training than is generally found in non-ICF/MR facilities. The 1981 Inspector General assessment found that the level of care required in an ICF/MR is inappropriate for certain institutionalized persons who could benefit from a more independent residential setting where less costly services would be more appropriate. 27/

27/ 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. LEGISLATIVE ACTIVITY REGARDING SERVICES
FOR MR/DD PERSONS

A. Background

Legislation was introduced in the 98th Congress by Senator John Chafee to increase the availability of Federal funding for community services and further reduce Institutionalization. S. 2053, the Community and Family Living Amendments of 1983, would have shifted Federal Medicaid funding for severely disabled persons from institutional care to community-based care in residential households and small facilities. Eligible facilities could not house more than three times the number of individuals in an average family household, or approximately nine persons. This bill would have affected ICFs/MR, other ICFs, and SNFs. Under this bill, an institution would have been allowed 10 years to reduce to zero the number of residents for whom ICF/MR reimbursement could be claimed (with limited exceptions). Certain smaller institutions with 16 to 75 beds were to be allowed 15 years. Facilities serving 15 persons or fewer at the time of enactment would not have been required to reduce resident population. After the transition period, Medicaid funds could only be used for institutional care of severely disabled persons if needed care were not available in the community and if the period of institutionalization did not exceed two years.

S. 2053 would have based eligibility for services on a functional definition of severely disabled persons taken from the Developmental Disabilities Act,

P.L. 91-517, as amended. The bill specified that the individual's impairment had to be manifest prior to age 50. The definition did not include persons between ages 21 and 65 whose primary diagnosis was mental illness.

Advocates for this bill stated that institutional care is detrimental to individual development and that Federal funds should only be used in family-scale settings where they believe more normalized development occurs. These persons state that strong Federal action is required to reduce institutionalization and to make Federal funds available in the community.

Those opposed to the bill stated that severely disabled persons require a continuum of service settings to meet individual needs and that facility size does not necessarily determine quality of care. Critics of the bill also stated that the eligible population under the bill would include a very large number of individuals (many more than are currently receiving ICF/MR services) and would thereby greatly expand the need for funds for services. 28/

B. Summary of the Community and Family Living
Amendments of 1985

1. Overview

In response to comments regarding certain provisions of S. 2053, Senator Chafee introduced a revised bill in the 99th Congress. S. 873 includes changes in some provisions of the previous bill, but continues the effort to 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

28/ For further discussion of S. 2053, see U.S. Library of Congress, Congressional Research Service. S. 2053 and the Transfer of Mentally Retarded Persons from Large Institutions to Small Community Living Facilities. Typed Report No. 84-554 EPW, by Mary F. Smith, February 21, 1984. Washington, 1984.

introduced in the House: H.R. 2523, which is identical to S. 873, and H.R. 2902, which includes minor differences. This description is generally applicable to both versions of the proposed amendments.

The proposed Community and Family Living Amendments of 1985 would encourage the development of community-based services for severely disabled individuals, and would allow about 15 percent of current 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 would not exceed three times average family household size, or approximately nine persons. States would enter into agreements with the Secretary of DHHS 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 make certain exceptions to the requirement that eligible facilities have no more than nine beds. Two types of facilities could continue to receive funding if they were in operation on September 30, 1985. Facilities of no more than 15 beds could continue to receive Federal funding if such facilities did not increase the number of residents after that date. Also, cluster homes could continue to receive funding if such homes did not increase the number of beds after September 30, 1985. A cluster home is defined as two or three facilities in proximity to another, each of which would meet the definition of community living facility except for the other residences in the

cluster. Another exception to the nine-bed limit is that Federal funds could be used in larger facilities if such facilities provided needed services unavailable in smaller facilities and if the period of care in the larger facility did not exceed two years after FY 2000.

The bill would authorize a limited amount of funds for use in the larger facilities, but the major thrust of the bill is to authorize funds for services to persons residing in a family home or a community living facility. A family home would include a natural, adoptive or foster home in which one or more severely disabled persons resided. A community living facility is defined as a single household, other than a family home, that provides living arrangements and care to one or more severely disabled persons, but the number of beds for such persons would be limited to three times the average family household size. A community living facility would be required to be located in a residential (neighborhood populated primarily by persons other than disabled persons. Such facilities are not to be unduly concentrated in any residential area. In addition, the facility would have to meet requirements for safety, sanitation, and staff training, and would have to cooperate in the provision of services specified in the written habilitation or rehabilitation plan for each disabled person.

Persons eligible for community and family services under the proposed amendments generally would be those disabled persons who are eligible for Medicaid and meet the definition of disability under the SSI program.

2. Community and Family Services for Severely Disabled Individuals

The proposed amendments would add a State plan requirement under the Medi-caid program specifying that community and family services are to be provided

to severely disabled individuals who reside in a family home or community living facility. States would be required to make available case management services to help plan and coordinate the individual's care, and, as necessary, individual and family support services to promote independence. Individual and family services would include personal care, domestic services, assistance with communicative devices and aids, and services provided to the family including respite care. Protective services would be required to be available as necessary to any severely disabled individual who was, or who except for his income or resources would be, eligible to receive services under Medicaid. These three mandated services would be required to be included in the State Medicaid plan by October 1, 1988.

States could choose to provide additional community and family services to assist severely disabled persons to live and function as independently as possible. These services would be set forth in an individual written habilitation or rehabilitation plan and could include diagnostic and assessment services, personal assistance and attendant care, assistive devices and communication aids, adaption of vehicles and housing for disabled persons, adult day care programs, services to family members, transportation, homemaker services, and out-patient rehabilitation facility services. These services could be provided in addition to any medical services for which the individual was eligible under the Medicaid program. Community and family services would not include room and board (except for up to 12 weeks per year as part of a support service); cash payments; any service for which the person was eligible under Medicare (title XVIII of the Social Security Act); any service for which payment was made under aid to families with dependent children (AFDC) (title IV of the Social Security Act); any education service which the State generally makes available without

cost; or any service in a hospital, skilled nursing facility or intermediate care facility. 29/

3. Eligibility

To be eligible for services under the proposed amendments, a person would have to meet the definition of severely disabled individual and be eligible for Medicaid.

Severely disabled individual is defined using the specifications for disability set forth under title II (SSDI) and title XVI (SSI) of the Social Security Act. This definition of disability is based on a medically determinable physical or mental impairment that can be expected to result in death or last 12 months or more. The impairment could result from anatomical, physiological or psychological abnormalities that can be identified by medically acceptable clinical and laboratory techniques. The bill further specifies that the definition of severely disabled individual would require the age of onset of the disability to have occurred prior to age 35, except in the case of a mental impairment which must have manifest itself prior to age 22.

Medicaid eligibility for most severely disabled individuals would be established through meeting the income and resource standards for SSI. Persons who are eligible for SSI are generally categorically eligible for Medicaid. In addition, 34 States allow Medicaid eligibility for medically needy persons who are not eligible for SSI. This program allows an individual whose income

29/ Most persons eligible for the proposed services would also be eligible for SSI. This income maintenance payment would be used for room and board. C Persons in an ICF/MR do not receive a monthly SSI payment sufficient to cover room and board because these expenses are included in the ICF/MR reimbursement. Institutionalized persons receive an SSI allowance of not more than \$25 per month.

and resources exceed SSI standards to receive Medicaid services if, after deducting medical expenses, the individual's income would meet SSI income requirements.

In addition to providing services to disabled persons eligible for Medicaid, the proposed amendments would give States the option of providing community and family services, or any other medical assistance, to severely disabled persons who spend, or are members of a family that spends, at least five percent of adjusted gross income for necessary care and services provided to the disabled family member.

4. Implementation Agreement

To receive payments under the Medicaid program after September 1, 1988, States would be required to enter into a community and family living implementation agreement with the Secretary of DHHS. The implementation agreement would assure that the State was reducing the number of severely disabled persons living in facilities which did not meet the size and location criteria for community living facilities. The agreement would also assure that the mandated community and family services were being provided. Private facilities are to cooperate in implementing the agreement. The implementation agreement would provide that staff in community living facilities receive adequate training or retraining. Also, training could be made available to parents caring for disabled family members at home.

The implementation agreement would include assurances that any severely disabled individual for whom a public agency arranges placement would have the opportunity to reside in a family home or a community living facility that was located close to the family of the disabled person. Disabled persons or their

representatives would be advised of their right of choice of service provider and their right to a fair hearing. Those who believed the services or placement were inappropriate would be provided an appeal and a hearing before an impartial hearing officer.

Under the implementation agreement, States would attempt to place severely disabled persons in a community facility rather than an institution, if possible, when placement out of the home was necessary. Severely disabled individuals living in facilities of 16 beds or more would be identified and their community living needs would be assessed. This would be accomplished by FY88 and reviewed annually thereafter. A transfer plan would be developed for each person to be moved from a larger facility into a family home or community living facility. An interdisciplinary team, including parents and client, would identify the community services needed and the disabled person or his advocate would be notified prior to the proposed transfer. Opportunity would be provided for appeal of the transfer plan on the grounds that proposed services were inappropriate, inadequate or unavailable. Public employees affected by the transfer of disabled persons from public institutions to community living facilities would be retrained and employed in the community and their rights and benefits would be preserved, if possible.

All public or private facilities receiving any State or Federal funds under title XIX (or under any other provision of law) which serve severely disabled individuals would be required to be accredited by a national accrediting body or certified as a SNF or ICF. Each community living facility or family home would be accredited by a national accrediting body or licensed by the State. In addition, States would be required to assure appropriate care for severely disabled individuals residing in a facility which ceased to receive payments under title XIX.

States would be required to maintain the level of service funding provided for severely disabled individuals that is currently supported with State funds.

5. Limitation on Payments for Services Provided in Large Facilities

The proposed amendments would limit the amount of Federal title XIX funding that could be used to deliver services to severely disabled individuals in facilities that did not meet the location and size requirements specified. Federal funds to these large facilities would be reduced to 15 percent of a base year by FY 2000. After this date, Federal funds for SNFs and ICFs of more than 15 beds which serve severely disabled individuals would receive a maximum per quarter of 15 percent of the greater of:

- 25 percent of the ICF/MR funds received for any fiscal year prior to October 1, 1985, as selected by the State; or
- the aggregate amount paid under title XIX for the quarter ending December 31, 1989, for SNF services and ICF services furnished to severely disabled individuals under age 65 in facilities having more than 15 beds.

The amount of base year funding as determined above for use in facilities of more than 15 beds would be adjusted in accordance with inflation.

6. Exemptions from Limitation

The limitation on payments to large facilities described above would not apply to SNFs and ICFs if such facilities met the size and location requirements specified in the amendments. That is, the 15 percent limitation on Federal payments starting in FY 2000 would not apply to facilities with less than 16 beds or to cluster homes, if such facilities were in operation on September 30, 1985. The limitation would also not apply to larger facilities if the individuals

served required services which were necessary to meet a therapeutic objective, which were not available in a family home or community living facility in the State, and which did not exceed two years' duration after FY 2000. In addition, the limitation would not apply to services received by persons age 65 and older, regardless of the size of the facility. Such persons could continue to receive services in the larger facilities, and funds for these services would not be affected by the reductions proposed in this legislation.

7. Reduction in Federal Matching Rate for Services Provided in Large Facilities

Beginning in FY89, the amendments would reduce the existing Federal matching rate for services to severely disabled persons under age 65 if such services were delivered in large facilities. For States having in effect a plan to implement the amendments, the Federal matching rate would be reduced one percent each quarter, or four percent each year, for 10 years. The matching rate could be reduced a maximum of 40 percent over this time period. That is, a State currently receiving a 50 percent Federal match could have the matching rate reduced to 30 percent for institutional services:

$$\begin{aligned} 50 \text{ percent} \times 40 \text{ percent} &= 20 \text{ percent} \\ 50 \text{ percent} - 20 \text{ percent} &= 30 \text{ percent} \end{aligned}$$

For States not having an implementation agreement, the Federal matching rate would be reduced two percent each quarter between FY89 and FY93, for a maximum of 40 percent over this five-year period. States without an implementation agreement after FY93 would have the matching rate reduced one percent per quarter from FY94 through FY98 for a total reduction of 60 percent over the 10-year period.

8. Protection of Rights of Severely
Disabled Individuals

To receive Federal funds for community and family services under the proposed amendments, States would be required to have in effect a system to protect and advocate the rights of severely disabled persons eligible for assistance under title XIX. The protection and advocacy system would be implemented by an agency that is independent of any agency delivering services to severely disabled individuals, has the authority to pursue legal and administrative remedies, and has access to the records of severely disabled individuals eligible for services under title XIX.

The amendments would provide the right to seek an injunction in Federal district court to any person injured or adversely affected by a violation of the proposed amendments by a State agency administering the Medicaid State plan. (The party bringing suit could recover reasonable attorneys' fees for this action if such party should prevail.

VII. DISCUSSION OF THE COMMUNITY AND FAMILY LIVING
AMENDMENTS OF 1985

A. Introduction

While all persons interested in care for severely disabled persons favor quality residential services, there is considerable disparity regarding the type of service setting considered most appropriate.

Advocates for the proposed amendments, who include 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 severely disabled 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. Among those in support of the proposed amendments are families of institutionalized persons who would prefer to have their disabled family member in a more normal community setting near the rest of the family. Some families may be able to care for the disabled member at home if community services were available to assist the family in this effort. These families would support the proposed amendments because funds could be made available to expand community residential facilities and community support services, thereby increasing the parents' choices of service setting.

Those opposed to the legislation, who also include professionals, parents of disabled persons, and other knowledgeable advocates, have stated that not all severely disabled 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 disabled persons are strongly opposed to the proposed amendments because they 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 and they do not want the Federal Government to legislate against their choice of care for their disabled family member. 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 may not provide the total care provided in one setting by an institution. Some parents are also concerned that under the proposed amendments reentry into an institution would be very difficult if the community placement did not work out.

B. Overview of Research Findings

Although empirical research on the subject 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 severely disabled persons.

A move from institutional to community settings tends to result in positive social adjustment and improved behavioral development for many disabled persons. 30/ 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. 31/

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 positive programming within the facility. That is, the community facility must be therapeutic as opposed to being merely custodial. 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. The more educated care providers tend to promote increased client interaction and increased contact with outside activities. 32/

(See appendix E for a selected bibliography that includes additional research on which this section is based.)

30/ Conroy, James, et. al. A Matched 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.

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

32/ Fernald, Charles. Too Little Too Late: Deinstitutionalization and the Development of Community Services for Mentally Retarded People. University of North Carolina at Charlotte, June 1984.

C. Caseload Estimates

Most severely disabled persons are maintained at home by families or reside in non-medical home care facilities or board and care homes. By making community facilities and services available to these groups, as the amendments propose, additional demand may be created on behalf of severely disabled persons not currently served in Medicaid-funded facilities. This phenomenon could increase total Federal expenditures. On the other hand, advocates of the legislation claim that severely disabled persons who do not receive needed services while living in the community may require costly institutionalization later as a result of such neglect.

An estimate of the number of persons who may be eligible for services under the proposed amendments must take into consideration several factors. The amendments would generally require that persons be eligible for SSI and Medicaid. The age of onset of the disability specified in the proposed amendments (prior to age 35, except for mental illness which is prior to age 22) would somewhat limit the number of disabled persons eligible for family and community services. Medicaid eligibility would not be required for severely disabled persons to receive protective intervention services. Also, States would have the option of making family and community services available to severely disabled persons not eligible for Medicaid if they or their families used at least five percent of their income on medical and support services for the disabled person. Severely disabled persons age 65 and over would be eligible for family and community services, but such persons could be provided institutional care without the proposed restrictions on funding.

An official of the Social Security Administration has provided data on the number of persons receiving SSI in FY85 with a date of onset of disability

in conformance with the proposed amendments. 33/ It is estimated that 940,000 blind and disabled persons whose disability was manifest prior to age 35 are currently receiving SSI. In addition, 75,000 persons with mental illness that originated prior to age 22 are receiving SSI benefits. According to these estimates, 1,015,000 SSI recipients (who are also generally eligible for Medicaid) would be eligible for family and community services, as specified in the proposed amendments.

As of this writing, there are no estimates available of the total number of persons who would be eligible for and in need of services under the proposed amendments or of the optional services States might choose to make available.

D. Size of Community Living Facility

The proposed amendments would require that community living facilities be limited to three times average household family size. It is the intent of the proposed amendments to make Federal Medicaid funding available to fund services in facilities that are believed by proponents to be most normalizing and least restrictive of personal liberty. A facility larger than approximately nine beds may not be easily integrated into an average neighborhood. The smaller facilities are intended to promote a home-like atmosphere with more personalized attention than is usually provided in larger facilities. Also, clients would generally be expected to leave the community facility during the daytime to participate in training or habilitation activities in the community, which could have the effect of further normalizing their lives. In addition, clients could

^{33/} Staren, Michael. Social Security Administration. Office of Supplemental Security Income. Division of Program Management and Analysis. Telephone conversation with the author, May 15, 1985.

utilize community recreation and health care facilities which could also promote community integration.

Those opposed to the proposed amendments have stated that a limit of three times average family size is arbitrary and that size of facility does not assure quality services. Some persons opposed to the amendments state that a large residential facility may be more appropriate for some disabled persons because a wider variety of activities and services can be made available on the premises. Also, opponents of the amendments have questioned where the capital would come from to construct safe, accessible housing for the multi-handicapped and nonambulatory persons now in institutions. In addition, neighbors' resistance to the development of community living facilities could be an obstacle to the integration of severely handicapped individuals into such neighborhoods.

E. Reduction of Federal Funding in Institutions

The proposed amendments would gradually reduce the Federal matching rate for Medicaid funds used in institutions, and starting in FY 2000, not more than 15 percent of base year funds could be used in such settings, with certain exceptions. These two provisions (reduced Federal funding and reduced Federal matching rate) would provide a disincentive to continue services in institutions and would provide an incentive to serve severely disabled individuals in community living facilities or at home. Services delivered to disabled persons living in community living facilities or at home would retain the current matching rates and would not be limited to an aggregate amount of funding.

1. Arguments in Favor of the Reduction
of Federal Funding in Institutions

Those in favor of the proposed amendments argue that these two disincentives are needed to reverse the current bias toward the use of Medicaid funding in large institutions and to make these resources available for community-based services. The ICF/MR regulation generally requires the delivery of comprehensive services in a single facility, thereby perpetuating large institutions. States have traditionally placed poor, chronically disabled persons in large institutions because that is where the Federal reimbursements could be made. Supporters of the proposed amendments state that all persons in institutions could benefit from transfer to the community if Federal funds were more readily available to expand community services. Under the proposed amendments, the higher Federal matching rate for community services would provide an incentive to States to place priority on these services. Long-range cost savings are possible by serving people in the community and preventing institutionalization according to this argument. This argument is based on evidence that community services tend to be less expensive than institution services. However, a thorough analysis of the cost issue would require an analysis of increased demand for services under the proposed amendments, and a consideration of total public costs (including SSI) involved in maintaining disabled persons in the community. Although severely disabled persons are currently being transferred from Institutional to community settings, the proposed amendments are needed to provide systematic long-term planning, advocacy, and secure funding for community services, according to supporters of the legislation.

In response to criticism that the proposed amendments would all but eliminate the option of institutionalization, advocates for the proposed amendments reply that States could continue institutional care using 15 percent of base

year funding. Due to the decrease in the Federal reimbursement rate for each institutionalized person, States would have to use substantially more of their own funds for services for each such person. This increase in the State per capita share would allow 15 percent of current Federal funding to serve approximately 25 percent of the persons currently institutionalized, according to advocates of the legislation.

2. Arguments in Opposition to the Reduction of Federal Funding in Institutions

Those opposed to the legislation state that limiting funding for institutions to 15 percent of base year amounts is arbitrary and is not based on knowledge of the needs of disabled persons. It has been recommended that a study be undertaken to assess the unmet needs of severely disabled persons and to determine the most appropriate living environments before deciding on the amount of funding that should remain in institutions. Persons opposed to the legislation state that a variety of service settings, including high quality institutional care and community-based services, should be available to meet the various needs of disabled persons. According to this position, there is a danger that the legislation could result in dwindling Federal resources for the most severely disabled persons left in the institutions. Opponents of the proposed amendments fear that a reduction of Federal funding to institutions could cause States to close institutions or sharply restrict institutional services, thereby reducing the availability of services felt to be necessary as part of the service system.

To meet ICF/MR standards in institutions, States have invested in the renovation of buildings and other improvements which required capital outlays. Under the legislation, States (and private ICFs/MR) could be required to absorb

the unamortized portion of these costs rather than pay for these improvements gradually through Federal reimbursements to the upgraded institutions.

The legislation proposes that the 15 percent ceiling on funds for institutional services be determined by ICF/MR funding used during the base year. Because use of this funding varies greatly from State to State (and Arizona and Wyoming do not now participate in the ICF/MR program), it might be argued that it would not be equitable to reduce funds using a formula based on prior usage. This approach could penalize States that have not chosen to participate extensively in the ICF/MR program or that have already reduced their institutionalized population.

Since the number of persons in public residential institutions decreased 42 percent between 1970 and 1984, no financial leveraging is necessary to stimulate deinstitutionalization, according to opponents of the proposed amendments.

F. Quality Control

Under the proposed amendments, States would enter into an implementation agreement with the Secretary stating that certain procedures would be undertaken to help assure quality services. Staff in community living facilities would be required to receive adequate training, facilities would be required to be accredited by a national accrediting agency or licensed by the State, and independent monitoring and reviews would be undertaken periodically. In addition, the Secretary would be required to conduct sample surveys to assess the quality of services being delivered. Institutions that continued receiving funding would be required to maintain the ICF/MR standards.

There is a concern that States could not monitor a massive influx of additional community facilities, and that there is insufficient financial commitment

under the legislation for monitoring and inspections. Those opposed to the legislation state that the ICF/MR regulation has provided the only national safeguard available to ensure that disabled persons receive adequate services and care. Removal of Federal funds from facilities covered by the ICF/MR standards could undermine effective public and private programs and penalize States with good institutional services, according to this argument. Also, there is concern that services in institutions would deteriorate as a result of the movement of most disabled persons from institutional to community settings.

G. Medically Fragile Clients and Clients
with Severe Behavior Disorders

One issue sometimes raised is the concern that medically fragile disabled persons who require 24-hour nursing care and frequent physician services may be served more efficiently in institutions where emergency services are available at all times. It is estimated that 25 to 30 percent of the institutionalized population is either medically fragile or has very severe behavior problems, and it is argued by some that these persons may be more appropriately served in facilities of more than nine persons.

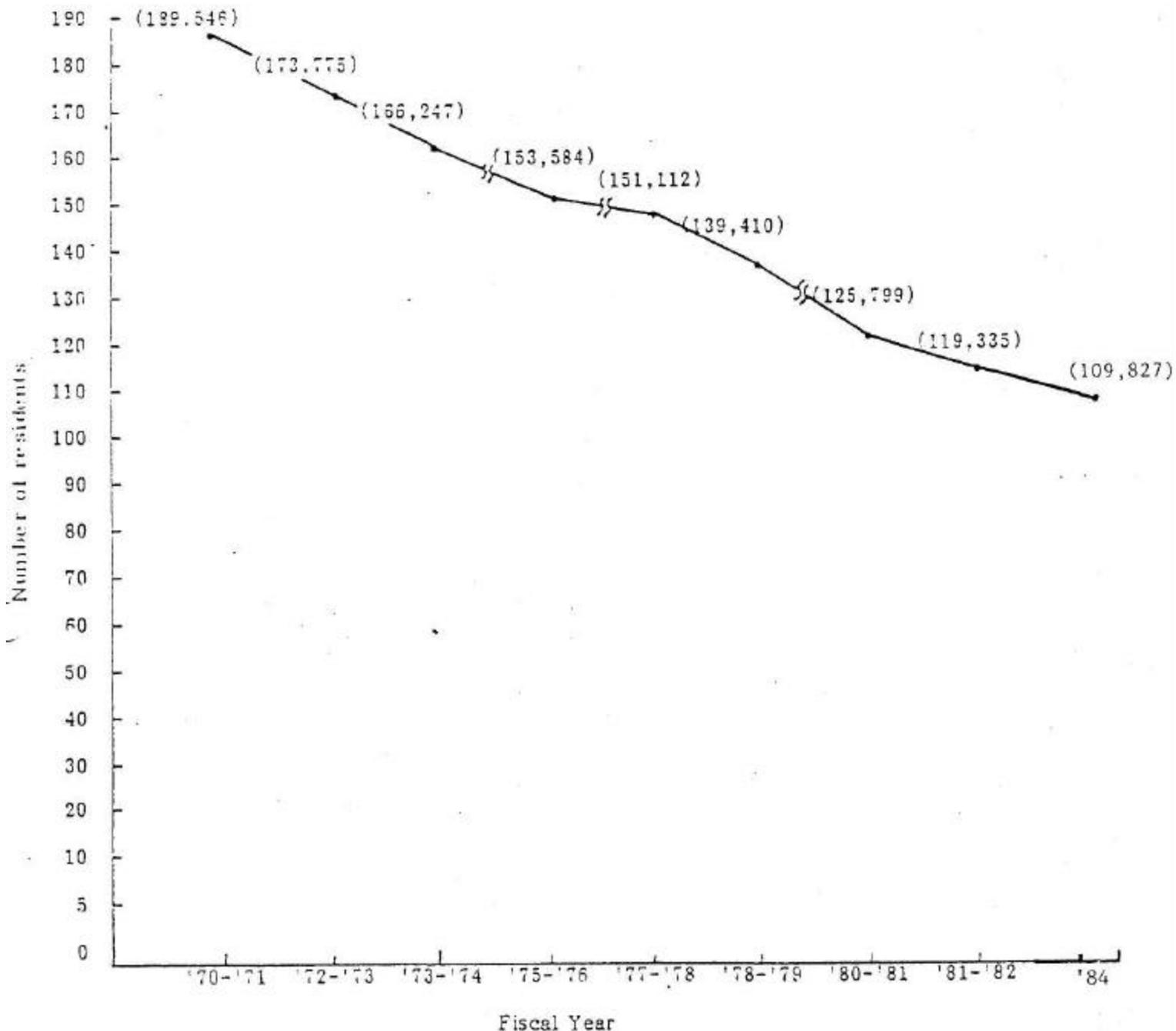
Advocates for the proposed amendments argue that these medically fragile clients and clients with severe behavior disorders can be appropriately served in family-scale facilities more humanely and with better results. However, if States should choose to serve these clients in institutions, this can be done using the 15 percent of base year funding authorized for such purposes under the proposed amendments, although with a significant reduced Federal share of costs.

H. Community Readiness

It has been argued that many communities are not ready to receive large numbers of disabled persons from institutions. It is clear that nearly all institutionalized disabled persons require care and/or supervision- Communities would need to develop facilities that were barrier-free and met life-safety codes required for severely disabled persons not able to respond appropriately to life-threatening dangers. The capital outlay for construction or renovation to develop such facilities could represent a considerable expense not addressed in the proposed amendments. It has been suggested that the legislation should be flexible so that States not able to meet the FY 2000 deadline could be given a longer time to expand community services before having Federal funds reduced to 15 percent of the base year amount.

It is the purpose of the proposed amendments to provide a strong incentive to States to develop and expand the use of family homes and community living facilities. The period between FY89 and FY 2000, when the amount of funding to institutions would be affected only by a change in the matching rate, is intended to provide some of the resources necessary to support community facilities. Also, existing private sector housing and housing funded through the Department of Housing and Urban Development could- be used for some of the community-based residences, and State funding can be sought, according to advocates of the legislation. It is argued that as long as nearly all Federal funding is used in institutions, communities will not have the resources to adequately expand services.

APPENDIX A: AVERAGE DAILY POPULATION OF MENTALLY RETARDED PERSONS IN PUBLIC RESIDENTIAL FACILITIES: FY 1970-FY 1984



Source: 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 U.S., Analytical Summary, by David Braddock, Ph.D., et al, University of Illinois at Chicago, p. 15.

APPENDIX B: PERCENT OF TOTAL PUBLIC AND PRIVATE RESIDENTIAL
CARE SYSTEM IN ICF/MR BEDS, BY STATE: FY82

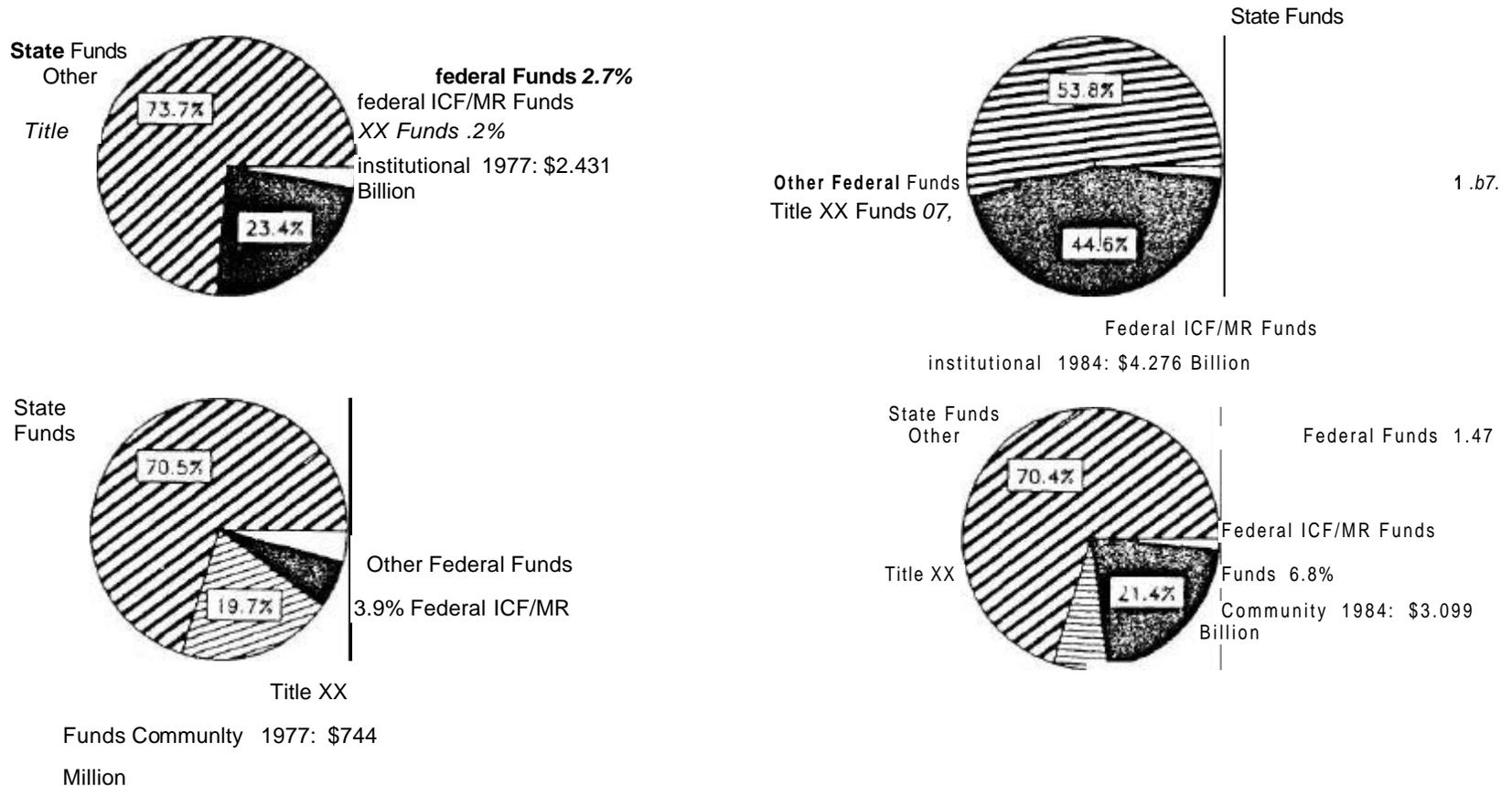
State	Percent
Minnesota	98.1%
Louisiana	95.9
Utah	88.8
Texas	88.6
Rhode Island	87.1
Virginia	85.1
Arkansas	83.8
Oregon	77.3
Alabama	75.6
Colorado	75.3
South Carolina	73.2
Georgia	72.8
Washington	72.3
Kansas... ..	72.3
Indiana	70.6
Tennessee	67.4
Kentucky	67.2
Delaware	67.1
New Mexico	65.4
Illinois	64.0
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

APPENDIX B: PERCENT OF TOTAL PUBLIC AND PRIVATE RESIDENTIAL
CARE SYSTEM IN ICF/MR BEDS, BY STATE: FY82--Continued

State	Percent
Maine	43.0%
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.

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NOTE: Community expenditures do not include maintenance funds (social security disability insurance or supplemental security income) or State or Federal funds used for special education.

Source: Braddock, David, Ph.D., et al. Public Expenditures for Mental Retardation and Developmental Disabilities in the United States. Analytical Summary, Public Policy Monograph No. 6. Published by the University of Illinois at Chicago. Mar. 1985. n. A-7.

APPENDIX D: ICFs/MR: PER DIEM PAYMENT RATES BY STATE
RANKED BY FY82 RATES

State	Per diem
Alaska.....	\$195
Massachusetts.....	140
New York.....	121
Pennsylvania.....	112
Michigan.....	107
Rhode Island.....	96
North Carolina.....	92
Nevada.....	91
Vermont.....	91
Idaho.....	87
Iowa.....	85
Georgia.....	82
Hawaii.....	81
New Jersey.....	81
Alabama.....	78
Florida.....	75
U.S. unweighted average.....	70
Missouri.....	67
New Mexico.....	67
Nebraska.....	67
Kentucky.....	65
Maine.....	64
District of Columbia.....	64
Arkansas.....	63
Illinois.....	62
Tennessee.....	61
Wisconsin.....	58
Colorado.....	57
Washington.....	57
Oregon.....	57
South Dakota.....	55
Louisiana.....	54
Oklahoma.....	54
Indiana.....	54

APPENDIX D: ICFs/MR: PER DIEM PAYMENT RATES BY STATE
 RANKED BY FY82 RATES—Continued

State	Per diem
Texas	\$ 52
Virginia	47
Ohio	47
South Carolina	46
Delaware	46
Utah	45
Mississippi	40
California	32
New Hampshire	32
Montana	30
Kansas •	28

Source: Health Care Financing Administration. Division of Medicaid Cost Estimates. Medicaid Program Characteristics Data, Feb. 24, 1984. 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.

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