

AN ANALYSIS OF MEDICAID'S INTERMEDIATE CARE FACILITY FOR THE MENTALLY RETARDED (ICF-MR) PROGRAM

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Chapter 1 MEDICAID COVERAGE
OF RESIDENTIAL SERVICES

Legislative History: Background

Effective January 1, 1972, there was added to the Title XIX Medicaid program a new optional service known as "intermediate care facility services for the mentally retarded and persons with related conditions," generally referred to as "ICF-MR." This amendment was a relatively little noted addendum to the section transferring authority for federal financial participation (FFP) in the cost of vendor payments for certain aged and disabled recipients of public welfare from Title XI of the Social Security Act to Title XIX. This transfer itself had far reaching consequences, of which, in recent years, the ICF-MR component has become a more conspicuous part.

ICF-MR care, not much heralded at its inception, now accounts for about 12% of all Medicaid expenditures. As is discussed at length in Chapters 6 and 7, its escalating costs resulted from a convergence of: (1) increased numbers of individuals covered as more facilities were certified; (2) the increased per resident costs of bringing facilities into full compliance with standards; and (3) inflation. Growth in all three of these factors has recently abated but the fiscal, regulatory, conceptual, programmatic, and political impacts of the program remain far reaching and controversial. However, at the time of enactment, the future was not apparent. A look at the historical development helps in understanding the present status of the ICF-MR program.

From one perspective, the inclusion of ICF-MR benefits in the Social Security Act represented some redress of discrimination of very long duration discrimination in federal law against people with mental disorders generally, and with mental retardation in particular, and above all against those who found themselves in public institutions. At one time, for example, states were permitted to withhold federal funds intended for crippled children from children with

remediable physical handicaps if they were also retarded. In the fifties Burton funds for construction of medical facilities were allocated psychiatric hospitals but not to infirmaries on the grounds of state facility the mentally retarded (Boggs, 1968). These examples resulted from admin interpretations, but the exclusions in the Social Security Act, beginning enactment in 1935, were quite deliberate and stemmed from a basic ph prevailing at the time.

A paradigm inherited from the 19th century assigned to state a government the responsibility for "indoor relief" typified by the county a while the more interesting beneficences associated with "outdoor relief" people living in their own homes) was assumed by private charity and ' associations (Kramer, 1981). Many "idiots" were to be found in all-purpose almshouses. For example, in 1880 the U.S. Census enumerated 5,86' persons" in almshouses, more than twice the number (2,429) then in p private institutions for retarded persons (Lakin, 1979). Since people w retardation or mental illness were seen as needing "indoor relief," their left to county and later to state government while the private sector "outdoor relief." Kramer (1981) concluded that:

Until the 1930's voluntarism was the American substitute for a genv social policy. It delayed the establishment of public programs income maintenance, housing, medical care, and other benefits instituted decades earlier in Europe. The Great Depression fin; made clear that voluntary institutions had been assigned a task t could not meet. (p. 65)

After five years of severe depression and declining state revenue! enacted Titles I, IV, and X of the Social Security Act in 1935 to provide funds through which states could take on the responsibilities for "out(of the most "deserving" classes - the elderly, the blind, orphans, "children deprived of parental support." It carefully precluded assisting with their own growing burdens of "indoor relief." Even the dese

would not get a federal penny when found in a public institution, or in any institution for mental diseases, public or private. The same prohibition extended to persons with disabilities when the aid to the permanently and totally disabled (APTD)--Titles XIV and XVI--were added in 1950.

Under the original Social Security Act, federal funds could be used only for cash payments to recipients of public assistance and did not reimburse state or local welfare departments for vendor payments for medical care needed by recipients. Many states discontinued direct payments to providers of medical care and, instead, included medical services as one of the recipient's needs in computing the amount of cash assistance payments. Payments, however, were low and certainly did not cover extraordinary health care needs, particularly those of aged, blind, and disabled people. In 1950, Congress reinstated the vendor payment system and this mode has persisted to the present day under Title XIX, and for in-patient care under Title XVIII.

The ten year period between 1950 and 1960 was marked by continued experimentation with rates and limits. A breakthrough which set the precedent for Medicaid came in 1960 with the Kerr-Mills Act. This established a separate program of medical assistance for the aged (MAA) including some not eligible for cash assistance (the medically needy). Reimbursement to the states was open ended and pro rated to their own outlays with a variable match favoring states with low per capita income.

During the period 1960 to 1965, considerable attention was paid to mental retardation at both the federal and state levels. Much of this was generated by the President's Panel on Mental Retardation, appointed in 1961 by President Kennedy. As a result of the passage in 1963 of P.L. 88-157, which added Title XVII to the Social Security Act, every state undertook a crash effort in "comprehensive statewide planning" in mental retardation; a parallel effort was also underway in mental health. In most states, public responsibility for

residential care of children and adults with mental retardation was at that time assigned to the state mental health agency.

During this period, the National Association of State Mental Health Directors was well organized and maintained an effective office in Washington under the leadership of Mr. Harry Schnibbe. Advocacy efforts and state program agencies focusing on the needs of mentally retarded individuals were less well organized and less prepared to provide an effective lobby on behalf of retarded persons. The National Association for Retarded Citizens (ARC), by far the largest advocacy organization for retarded persons, maintained its offices in New York City and until 1969 did not even have a Washington office. In 1966, following discontinuation of the Office of Special Assistant to the President for Mental Retardation, created by President Kennedy, the President's Committee on Mental Retardation (PCMR) was created by executive order of President Johnson; the committee did not then, nor has it since represented a major active and visible political force outside of the executive branch. However, Robert Gettings, a staff member of PCMR from 1968 to 1970, became the first and current executive director of what is now the National Association of State Mental Retardation Program Directors (NASMRPD), an organization given impetus by state planning efforts under Title XVII. NASMRPD was without a Washington office or staff until late 1970. Similarly, the American Association on Mental Deficiency (founded in 1876) had no ongoing staffing, although it was engaged in a project, supported with a federal grant, that turned out to be critically important in the development of the ICF-MR programs: writing standards for facilities for persons with mental retardation. AAMD was then based in Columbus, Ohio. The personal advocacy of Eunice Kennedy and Sargent Shriver were strong until their departure for France at the start of the Nixon administration, but their efforts focused primarily on implementation of the specific mental retardation-related Kennedy legislation (including what later became the Developmental Disabilities

Act [P.L. 91-517]).

The people most able to focus on the potential impact of the global "great society" legislation were the state welfare directors, among whom Wilbur Schmidt (Wisconsin), Norman Lourie (Pennsylvania), Morris Hirsch (Minnesota), and Lloyd Rader (Oklahoma) stand out. They had a friend and colleague in Wilbur Cohen, who became Johnson's Secretary of Health, Education, and Welfare. Rader was in a particularly influential position because of the key positions held by members of the Oklahoma delegation in both houses of Congress and because his statutory power base and bipartisan support in Oklahoma made him relatively independent of gubernatorial direction. (Rader's Department of Social and Rehabilitation Services included mental retardation but not mental health.) But with all the power and responsibility brought to state welfare directors by Medicaid (enacted in 1965) and by concurrent changes in the public assistance titles, it took a little while and a little prompting for them to realize that these new laws had potential for benefiting people disabled by mental retardation, and also potential for harming them when their interests were not considered in the context of competing groups, such as elderly and mentally ill people. The problems for people with mental retardation in the welfare system began to be apparent even before Medicaid.

Both before and after 1965, the National ARC was being confronted with concerns relayed by its own state member units and from superintendents of state institutions in a few states about the erratic impact of certain provisions of the Social Security Act on care of people with mental retardation. For example, on March 30, 1964 the Illinois Council for Mentally Retarded Children wrote:

You may have heard of the recent development in Illinois where the Illinois Department of Mental Health is planning to have a mass exodus of approximately 2,000 patients from Lincoln and Dixon State Schools, placing them in proprietary nursing homes and sheltered care homes. They predict that they will accomplish this mass movement within eighteen months.

Inherent within their plan is to give eventually absolute discharges to these patients. Only the patients in Lincoln and Dixon who would be eligible for public assistance will be selected. It is our belief that the Illinois Department of Public Aid would not be able to provide the supervision of the patients which would be necessary to assure that their best welfare in the proprietary nursing homes is being considered. Our concern in this area has been confirmed by some of the HEW personnel in the Region V office as well as some of the Illinois Department of Public Aid staff.... The Department of Public Aid is saying quite clearly that the extent of their service cannot go much further than determining financial eligibility for public assistance.

New problems surfaced when Medicaid was finally enacted in 1965; it carried forward many of the structural characteristics of Kerr-Mills and extended medical assistance to people in the categories of the blind, the disabled, and dependent children and their families. This was a step forward for people disabled by retardation, but Title XIX also carried forward the original exclusions of otherwise eligible persons in public institutions (other than medical institutions) and also in any institutions for mental diseases or tuberculosis (both private and public), thus further fostering the policy responses reported from Illinois.

There was one exception. States could claim FFP in their costs for treating people over 65 in institutions for mental diseases (or tuberculosis) if certain conditions were met. Up until that time, the term "institution for mental diseases" had been broadly interpreted to include any in-patient facility whose primary function was care of mentally ill or mentally retarded persons. In an effort to use the new entitlement to leverage improvements in psychiatric hospitals, the American Psychiatric Association prevailed upon the Department of Health, Education, and Welfare to incorporate in its regulations a more precise definition that could form a basis for setting standards using Joint Commission for the Accreditation of Hospitals criteria. This revised definition excluded institutions for the mentally retarded. (See 42 CFR S.435.1009)

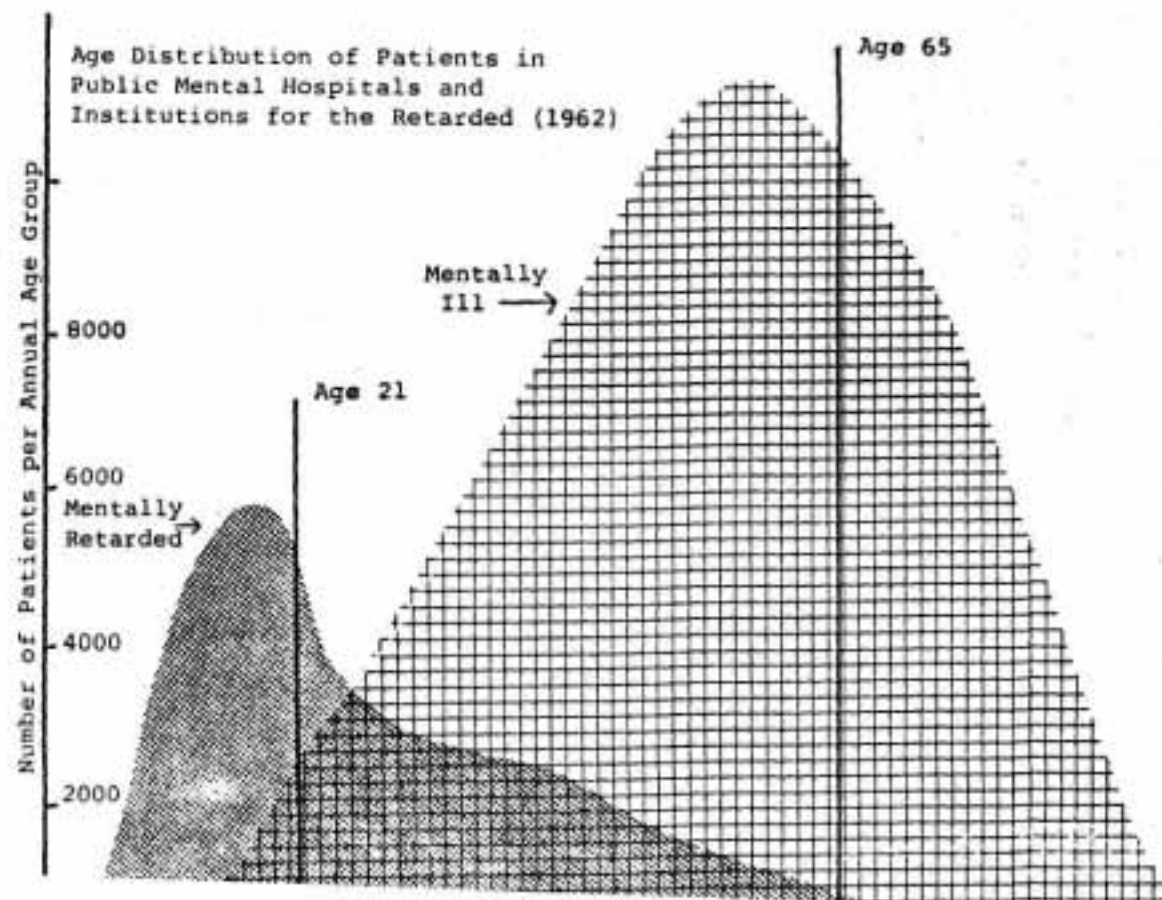
The immediate effect was to Qualify otherwise eligible adult residents of private facilities specifically licensed to serve persons with mental retardation. Such persons who met the state income and assets tests for aid to the permanently

and totally disabled (APTD) could thus receive both APTD (and later SSI) and ambulatory, hospital, or skilled care under Medicaid, for all of which they had previously been disqualified. This development did not have great immediate impact because only a small proportion of persons identified as retarded were receiving care in such private licensed facilities at the time. However, the change opened up state options to "reprivatize" the state institutional care systems that had grown from 60,400 before the Depression (1928) to 191,600 in 1966. It also permitted states to give greater emphasis to the purchase of care from specialized private licensed facilities as distinct from generic board and care or nursing homes.

In some states, however, welfare directors did not understand this change, and continued to declare ineligible mentally retarded persons who were being cared for in non-psychiatric facilities when these were licensed by the state department of mental hygiene or equivalent body. Unfortunately, this interpretation inhibited the development of community residential facilities specifically for retarded people in those states which were progressive enough to have special licensing provisions for such facilities. It took time to overcome these interagency barriers.

A second effect of Title XIX was to continue the prohibition of any reimbursements to states on behalf of elderly residents of state facilities for retarded people, while simultaneously causing states to focus on the urgent need to upgrade the physical plants and quality of care given elderly patients in state psychiatric hospitals in order to take advantage of their new eligibility. Figure 1.1 illustrates why the discrimination against elderly persons who were retarded was not a major concern in and of itself. The number of aged persons in mental hospitals was substantial (144,000 on June 30, 1964; NIMH, 1975); the number in "state schools" was small. The indirect result, however, was the diversion of state resources to upgrading their mental hospitals while neglecting their facilities for

FIGURE 1.1



retarded persons precisely at a time when their resident populations were reaching their all time peak.

Concern over this trend was soon followed by another concern—incentive given to states to convert their public institutions into Skilled Nursing Facilities (SNFs), whose residents would then qualify as patients entitled to inpatient coverage under Title XIX. While the standards for SNFs did require these facilities to meet higher life safety criteria and to have more professional nursing staff than were then provided in most state institutions, the SNF standards were addressed primarily to aging persons and emphasized medical needs to the exclusion of "developmental" programming considered more appropriate for children and young adults.

This SNF option was explicitly authorized by the Medical Services Administration's (MSA) 1966 Handbook Supplement D. Section 4620.3 reads:

Federal Financial Participation may be claimed in medical assistance under the State plan for individuals (regardless of age) in institutions for the mentally retarded (as contrasted with institutions for the care and treatment of individuals with mental diseases) which meet the definitions in D-5141, item 1 or D-5141, item 4.1.

D-5141, item 1 defined in-patient hospital services; D-5141, item 4.1 defined skilled nursing services, both in general terms.

In 1969 Connecticut and Missouri reported claims of approximately \$250,000 for the care of retarded individuals outside of state institutions. This was the tip of the iceberg revealed by an MSA study resulting in a report on "Assistance to Mentally Retarded Individuals in State Institutions Under Title XIX for the Year ending 6/30/69."

The data reported for the 11 states which were applying "Supplement D" options to public facilities are contained in Table 1.1. MSA also conducted a follow up study in California and concluded that "eighty percent of records reviewed indicated that the recipient did not meet the definition of a patient needing skilled nursing or hospital care." (Memo HM 9 from SRS Acting

Table 1.1

Payments Under Title XIX for Individuals Residing
in State Institutions for Mentally Retarded People
Fiscal Year 1969

	TYPE*		ELIGIBLE	PATIENT	TOTAL	FEDERAL
	H	S	PATIENTS 6/30/69	DAYS FY 69	COST (Title XIX)	SHARE
CA	x		4,356	NA	\$ 23,084,671	\$11,042,335
GA		x	389	69,428	503,161	410,982
IL	x		293	93,148	815,294	407,647
KS	x		384	147,571	2,399,504	933,443
MD	x		858	344,796	3,404,951	1,702,476
NY		x	12,828	5,049,708	67,903,003	33,951,501
OK	x		2,057	120,764	2,192,068	1,525,898
PA		x	9,830	3,425,873	35,962,887	15,838,980
TX		x	3,278	1,392,176	9,567,664	7,633,082
UT**	x			22	1,571	1,025
			276			
		x		34,808	256,122	167,094
WI	-	x	3,272	1,217,784	18,542,679	10,509,998
Subtotals						
Hospitals				706,310***	30,898,059	15,612,824
Sk. Nursing				11,795,903	136,955,102	71,448,883
TOTAL			37,821		\$167,853,161	\$87,061,707

- H = hospital

i

- S = skilled nursing facility

**Utah hospital care provided outside state institution

***Without California

Two states claimed funds under Title XIX for retarded patients in private facilities: CT - \$91,479; MO - \$159,469

Source: Social and Rehabilitation Service, 1970

Commissioner Thomas Laughlin to All SRS Regional Commissioners, dated January 7, 1970.)

The General Accounting Office (GAO) also studied the California program and reported to Congress recommending more rigorous enforcement of requirements for individual evaluation and treatment under Title XIX (GAO, 1970). Specifically, the GAO report faulted existing practice in California (probably occurring also in other states at the time) on two primary grounds: 1) skilled nursing facility (SNF) levels of care were not actually being provided to the institution residents, and 2) for the vast majority of residents, SNF levels of care were neither needed nor even appropriate. Of a more general concern to the GAO reviewers was whether the existing SNF standards in medically-oriented facilities constituted proper guidelines for a mental retardation facility. However, California institutional cost data revealed that, because meeting the SNF or hospital standards had not required California to double its per capita expenditures (they increased from a 1965 state average of \$3,800 per annual average resident to about \$6,000 per average annual resident in 1969 after certification as SNF under Title XIX), its receipt of FFP equal to 50% of total institution costs was resulting in a net benefit to the state treasury.

Wisconsin was another early user of Medicaid in its public institutions. Table 1.2 represents its actual and projected collections for SNF care of residents in its three "colonies." Late in 1968, the Superintendent of Central Colony, Harvey Stevens (who was also a national leader in the field of mental retardation), was among the first to protest the fact that federal funds in excess of those needed or actually used to upgrade the level of care in Central Colony to that of a SNF were in effect being used to replace state appropriated funds rather than being totally committed to the improvement of the Colony's own program. This was an example of the perverse working of the generalized or aggregate temporary "maintenance-

Table 1.2
Actual and Projected Collection for SNF Care in Three Wisconsin
Mental Retardation Institutions

	FISCAL 66-67			FISCAL 67-68			FISCAL 68-69		
	Northern Colony	Southern Colony	Central Colony	Northern Colony	Southern Colony	Central Colony	Northern Colony	Southern Colony	Central Colony
Projected % Population Enrolled	84.86%	91.48%	96.48%	84.86%	91.48%	96.48%	84.86%	91.48%	96.48%
Number of Eligible weeks of care based on population projection	46,274	40,809	29,499	66,555	58,593	49,941	69,691	60,818	55,338
Average weekly rate of per capita cost	\$65.28	\$72.05	\$123.80	\$88.96	\$96.19	\$144.85	\$100.74	\$108.38	\$160.44
Fiscal Year Gross Billing	\$3,020,952	\$2,945,930	\$3,652,891	\$5,920,732	\$5,635,767	\$7,234,053	\$7,020,741	\$6,591,454	\$8,878,428
Net Billing to Blue Cross	\$2,718,857	\$2,651,337	\$3,287,682	\$5,328,659	\$5,072,190	\$6,510,648	\$6,318,666	\$5,932,309	\$7,990,585
Total of all Net Billings			\$8,657,796			\$16,911,498			\$20,241,562
Federal share of payment 56.68%			\$4,007,238			9,585,437			\$11,472,917

Blue Cross was billed as the Medicaid intermediary. The net billing above is derived by deducting an estimated 10% from the gross billing for such other collections as Social Security, Railroad Retirement and Veterans Administration benefits, family contributions toward care charges, private insurance payments, Title XVIII, Part A Medicare benefits, etc.

In the three fiscal years above the anticipated federal funding to the program is expected to be 125,965,592. In this program 56.68% of monies is contributed by federal government. 20% to 55% of the non-federal share (43.32%) comes from county of legal settlement of enrolled patient (based on county's ability to pay) and 45% to 80% is derived from State General Purpose revenues.

Source: Central Wisconsin Colony and Training School: The Wisconsin Medical Assistance Program - Report of May 15, 1968 (duplicated)

of-effort" clause (Section 1117 in effect from 1966 to 1968) which had been included in the 1965 legislation; it prohibited a state from spending less than the combined total of its pre-1966 non-federal public assistance and medical assistance expenditure. There was also a more specific clause (Section 1903 (b)(1) repealed in 1972) protecting the state's mental health expenditure level as a condition of receiving FFP in costs of care of elderly patients in mental hospitals.

It was in this period of expanding attempts by states to secure FFP in defraying the rapidly increasing costs of state institution care (see Chapter 7), of concurrent concerns about the appropriateness of the models of care then eligible for funding (especially in public facilities for retarded persons), and of concerns about the extent to which the additional federal contributions secured were actually being used to improve the care received by the residents, that the ICF-MR program was conceptualized. Intermediate Care - The Evolution of a Concept and Statute

In the mid-to-late 1960s, institutions for mentally retarded people were not the only places where adults were being reclassified to fit the 1965 Medicaid criteria. Large numbers of elderly people rapidly became patients in SNFs, a development of which the Senate took prompt note. "Intermediate care" for the elderly and disabled adults was authorized as a "non-medical" service in 1967. The rationale for this action is made clear in the following excerpts from the Senate Report and Conference Report respectively on H.R. 12080, the Social Security Amendments of 1967.

Intermediate care homes

Good skilled nursing home care is expensive. At the present time, under the medical assistance program, skilled nursing home services are offered with Federal sharing in the cost. These homes have relatively high standards for approval. Serious questions have been raised with the committee concerning the limitation, under the Federal law, on the kinds of facilities for which Federal sharing is available. The committee believes that a strong case exists for introducing another level of care for which vendor payments would be available.

At the present time old-age assistance recipients whose primary need is for care in an institution other than a skilled nursing home are frequently classified as in need of "skilled nursing home" care and placed in such institutions because of a decided financial advantage to a State under present matching formulas.

Title XIX does not provide Federal matching funds for institutional care which provides more than room and board but less than skilled nursing home care—only for "skilled nursing home care." But, if a State classifies a needy individual as in need of "skilled nursing home care" it can receive unlimited Federal matching funds. If it classifies him as in need of other institutional care, the State receives the standard old-age assistance cash matching, which is available only up to \$75 a month on the average.

Thus, the Federal and State governments often may pay upwards of \$300 a month for skilled nursing home care for a patient who could be adequately taken care of in another type of institution for \$150 or \$200 a month. The American Nursing Home Association and the Department of Health, Education, and Welfare both advised the committee that as many as 50 percent of the assistance recipients in skilled nursing homes are not, in fact, in need of skilled nursing home care. Thus, the committee has adopted an amendment to provide for vendor payments in behalf of needy people qualifying for OAA, AB, or APTD who are or who should be in intermediate care homes, and that the rate of Federal sharing be the same as the formula in title XIX if the State elects to be paid under that formula. Intermediate care homes would be defined and licensed by the States and would be those institutions which provide services beyond ordinary board and room but below the level of skilled nursing homes.

This amendment could result in a reduction in the costs of title XIX by enabling States to use lower cost facilities more appropriate to the needs of thousands of persons, thus avoiding the higher charges for skilled nursing homes when care of that kind is not needed. This provision would remove the incentive to classify such people as "skilled nursing home" patients.

The amendment would also solve many of the problems encountered by small institutions which are now technically classified as nursing homes but which basically provide lesser care. They cannot possibly meet title XIX standards for skilled nursing homes and while often appropriate to provide the types of care envisaged by this amendment they might very well be forced out of business when required to meet title XIX standards. Such facilities are frequently the only nonhospital institutions available in rural areas and do meet a legitimate need for care less than that found in skilled nursing homes.

The committee expects that the institutions covered by this provision will be subject to periodic professional review and audit as to the care provided and its appropriateness for individuals in such institutions. The Secretary of Health, Education, and Welfare is expected to assist States in developing suitable review procedures to meet these objectives. (Senate Report 744 on H.R. 12080, November 14, 1967, pp. 188-9)

Later in the report a description is provided of the proposed new level of care:

Section 231. Assistance in the Form of Institutional Services in Intermediate Care Facilities

Section 251(a) of the bill amends title XIX of the Social Security Act (as amended by sec. 209 and 249 of the bill) by adding thereto a new section 1121.

Section 1121(a) authorizes any State which has in effect an approved State plan for old-age assistance, aid to the blind, aid to the permanently and totally disabled, or aid to the aged, blind, or disabled, to modify such plan on or after January 1, 1968, to include therein payments for institutional services in intermediate care facilities for individuals who are or would be (if not receiving institutional services in intermediate care facilities) entitled to assistance under such plan in the form of money payments.

Section 1121(b) requires any modification pursuant to section 1121(a) to provide that benefits in the form of institutional services in intermediate care facilities will be provided only to individuals who—

(1) Are or would be (if not receiving institutional services in intermediate care facilities) entitled to receive aid or assistance under the State plan in the form of money payments;

(2) Because of their physical or mental condition (or both), require living accommodations and care which, as a practical matter, can be made available to them only through institutional facilities; and

(3) Do not have such an illness, disease, injury, or other condition as to require the high degree of care and treatment which a hospital or skilled nursing home (as that term is employed in title XIX of the act) is designed to provide.

Section 1121(c) provides that payments to any State which modifies its approved state plan (referred to in sec. 1121(a)) to provide recipients thereunder with benefits in the form of institutional services in intermediate care facilities shall be made in the same manner and from the same appropriation as payments made with respect to expenditures under the State plan so modified, except that, with respect to the State's expenditures for the cost of benefits in the form of institutional

services in intermediate care facilities for any quarter, the Secretary shall if the State so elects pay the State an amount equal to the Federal medical assistance percentage (as defined in sec. 1905(b) of the act).

Section 1121(d) provides that except when inconsistent with the purposes, or contrary to any provision, of section 1121, any modification, pursuant to section 1121, of an approved State plan shall be subject to the same conditions, limitations, rights, and obligations as obtain with respect to such approved State plan.

Section 1121(e) defines the term "intermediate care facility" as an institution which (1) is licensed, under State law, to provide the patients or residents thereof, on a regular basis, the range or level of care and services which is suitable to the needs of individuals described in section 1121(b) (2) and (3), but which does not provide the degree of care required to be provided by a skilled nursing home furnishing services under a State plan approved under title XIX of the act, and (2) meets such standards of safety and sanitation as are applicable under State law; except that in no case shall such term include an institution which does not regularly provide a level of care and service beyond room and board. (Senate Report on H.R. 12080, November 14, 1967, pp. 309-310)

In Conference Committee the House conferees accepted the amendment creating the ICF authority with two provisions and a clarification of intent:

Amendment No. 258: The Senate amendment added to the House bill a new section (251), amending title XI of the Social Security Act by providing (in a new section 1121) for Federal financial participation under titles I, X, XIV, and XVI in vendor payments in behalf of certain aged, blind, or permanently and totally disabled individuals whose condition does not require care in a skilled nursing home or hospital but does require living accommodations and institutional care available through intermediate care facilities. Federal matching would, if a State elects, be at the same rate as for medical assistance under title XIX.

The House recedes with amendments providing that (1) intermediate care facilities must meet the safety and sanitation standards applicable to skilled nursing homes, and (2) Christian Science sanatoria may be considered to be intermediate care facilities with respect to such services. It is the intention of the conferees for the House that providing services in intermediate care facilities is not to be taken as authorizing, or acting as a precedent for, the furnishing of custodial care of a type which merely provides, for welfare recipients in the program specified, room and board with no personal or other services. (Conference Report on H.R. 12080, House Report 1030, December 11, 1967, p. 69)

The documentation is given here in some detail because in recent years speculation has sometimes replaced available harder evidence on the context in which the intermediate care program was created. Clearly, as well documented in

Senate and House Reports, "over care" and consequent excessive costs were the primary concern in developing the intermediate care option. In addition, the amendments responded to the desire of states and providers for the security of vendor payments directly to the provider as opposed to cash assistance to their clients. (The proposed Section 1121 was limited to adults entitled to cash assistance as aged, blind or disabled persons.)

There was no doubt from the start that persons eligible for APTD on the basis of a disabling degree of mental retardation could take advantage of the ICF benefit in any state including the ICF option in its state welfare plan (Title XIV or XVI). In the light of the earlier decision to discontinue the previous practice of disenfranchising retarded persons living in facilities licensed specifically for their care, a new avenue for funding private care, including community care, opened up. In view of the subsequent debates about whether Congress intended to authorize ICF status for small facilities, it is well to look back at the material just quoted from the Senate Report of 11/14/67. A whole paragraph is devoted to the utility of the ICF model for small facilities, facilities seen as too small to be operated economically under the stiffer SNF rules. Data gathered by the National Center for Health Statistics from the periodic National Master Facility Inventory covering this period consistently document that small private "homes" for nursing or personal care were the most common. The average size in 1967 was 44; nearly 40% had fewer than 25 beds, with a substantial fraction having from 3 to 9 beds (DHEW Publication No. HSM 72-1509; DHHS Publication No. (PHS) 81-1819). In 1967 the applicability of the ICF model to small facilities was simply not an issue. Private facilities tended to be small; public facilities tended to be larger. The potential of this less medical model of care for adults with mental retardation caught the attention of advocates of improved programs for mentally retarded persons. Although per capita rates in ICFs were intended by Congress to be less than for SNF care, the actual requirements of this level of care permitted more

flexibility and hence provided the opportunity to emphasize developmental rather than medical goals with reimbursement levels above those for cash aid to the disabled living in their own homes.

Late in 1967 the National Association for Retarded Children (now ARC/US) issued a "white paper" calling on DHEW to use their rule making authority constructively. The last paragraph reads:

It is urgent, therefore, that the regulations to be written to administer the new Section 1121 on intermediate care be drawn with the following positive objectives in mind:

(1) the development and improvement of intermediate care facilities, both public and private, which offer programs specifically designed to benefit the mentally retarded.

(2) the encouragement of existing public institutions to meet this need by providing programs which conform to requisite standards for "intermediate care."

(3) the maintenance of effort on the part of all institutions receiving disabled retarded persons who could be eligible for the OAA and the APTD payments under the intermediate care amendment and the use of the vendor payments which will become available to them to further extend and improve the level of care.

To this end the definitions of "intermediate care" should include facilities, public or private, which provide programs of care, rehabilitation and/or treatment which are appropriate to the needs of some or all classes of needy retarded adults who meet the disability or old age requirements for categorical assistance. (National Association for Retarded Children, 1967).

In fact some doubt existed as to whether Section 1121 could override the existing prohibition of federal matching funds to "public institutions" other than "medical institutions." This was explored by NARC with the Department of Health, Education, and Welfare. In a letter dated May 24, 1968, in response to an inquiry from Eleanor Elkin, President of NARC, Secretary Wilbur Cohen clarified the department interpretation as follows:

5. Intermediate Care Facilities

We do not believe that Section 1121 of the Social Security Act, which was enacted as part of the Social Security Amendments of 1967,

affords broad-scale opportunity to participate in the costs of mentally retarded persons in public institutions. In enacting this Section Congress did not modify, and we do not believe it was their intent to modify, the prior exclusions from the assistance programs of "payments to or care in behalf of any individual who is an inmate of a public institutions (except as a patient in a medical institution)." Insofar as the mentally retarded in public institutions are concerned, we believe that eligibility under the new Section would depend on whether or not the institution could meet the criteria of a public medical institution. Some institutions which do not qualify as hospitals or skilled nursing homes under title XIX still qualify as public medical institutions. Insofar as they do, the new Section will be helpful for this group of individuals.

This interpretation lends some credibility to the actions of a few states which sought to use Section 1121 funding for persons in state facilities, but this practice was later criticized sharply in a Senate staff report (Medicare and Medicaid - Problems, issues, and alternatives - Committee on Finance, U.S. Senate, February 9, 1970). The report concluded that such a use was clearly not authorized in the ICF legislation, but noted the future possibility for enabling legislation:

Some States Attempt to Outflank Legal Prohibition to Gain Federal Funds

Third, in an effort to substitute Federal dollars for State dollars, several States are seeking to classify as intermediate care facilities, publicly-owned institutions for the mentally retarded. Payments for care of the mentally retarded in such public institutions is not, at present, eligible for Federal matching under Medicaid.

While the Congress may desire at some future date to afford Federal matching funds for care of mentally retarded persons in public institutions, Sections 6(a) of Title I, 1006 of Title X, 1405 of Title XIV, and 1605 of Title XVI, of the Social Security Act coupled with Section 121(b) of the Social Security Act Amendments of 1965, clearly appear to preclude Federal matching under existing law. Titles I, X, XIV, and XVI prohibit payment for care in a public institution, other than a medical facility. Thus a State would have to classify an institution for the mentally retarded as a medical facility in order to except it from the statutory prohibition. However, Section 121(b) states:

"No payment may be made to any State under Title I, IV, X, XIV, or XVI of the Social Security Act with respect to aid or assistance in the form of medical or any other type of remedial care for any period for which such State receives payments under Title XIX of such Act, or for any period after December 31, 1969."

Therefore, if the institution for the mentally retarded were called a medical facility, no payments could be made except to the extent they were qualified and made through Title XIX. The Department of Health, Education, and Welfare does not classify mental retardation as a "mental disease" and the latter is the only form of mental condition coverable under the provisions of Title XIX. (p. 100)

It might be argued that Section 121(b) as cited does not specifically mention Title XI, but the staff report leaves little doubt about Congressional intent at that time.

One purpose of "Section 121(b)" (enacted in 1965, amended in 1972) was to prevent the states from using federally financed welfare payments to pay for substandard institutional care or to otherwise circumvent Medicaid rules. The term "medical institution" as currently defined (42 CFR 435.1009) includes but is not limited to Medicaid certified inpatient facilities. An otherwise eligible person residing in a public or private "medical institution" which is not certified as an inpatient facility under Title XIX may receive (1) SSI and (2) Medicaid coverage for certain medical care which is not "provided by" the institution, e.g., visits to the office of a physician or dentist, or acute care in a hospital. Some states use these mechanisms to cover some part of the costs incurred by or for persons who occupy uncertified beds in public medical institutions, or public educational institutions (such as vocational boarding schools). The general prohibition against allowing SSI, public assistance, or Medicaid payments to or on behalf of an "inmate of a public institution" other than a "medical institution" still pertains. (See 45 CFR 233.145)

The Legislative History: Transferring ICFs to Title XIX

The 1970 Committee on Finance report closed the debate on the use of the ICF program to provide care in state institutions, but it certainly did not end efforts to secure FFP for improving the quality and defraying the rapidly accelerating costs of such programs. These efforts would bear fruit nearly two years later.

In May of 1970 the House Ways and Means Committee reported out H.R. 17550

with a rather emphatic exclusion of ICF program benefits for state institution residents; Section 1121(e) was to be amended by adding "Effective July 1, 1970 the term intermediate care facility shall not include any public institution (or distinct part thereof) for mental diseases or mental defects." Noting this, NARC convened on September 1-2, 1970 a working group of individuals who were actively involved in welfare reform efforts currently underway. The key actors who met with members of the ARC Governmental Affairs Committee and staff included: former HEW Secretary Wilbur Cohen, generally recognized as the major architect of the original Social Security Act as well as many of its amendments, Leonard Ganzer, Director of Mental Health in the Wisconsin Department of Welfare, and Chair, Committee on Child Mental Health of the National Association of State Mental Health Program Directors, Mr. Harry Schnibbe, Executive Director of the same organization, Mr. Lloyd Rader, head of the Oklahoma Department of Social and Rehabilitation Services, which included the state's mental retardation program along with its welfare and Medicaid functions, and Mr. Leo Irwin, who had recently retired as Chief Counsel of the House Ways and Means Committee.

Of the eleven topics on the agenda, six related directly to the dilemmas surrounding the use of Title XIX to fund services for people with retardation. It was pointed out that some of the maneuvers designed to benefit other target groups had produced actual or potential negative impacts on the quality of care of retarded people whereby FFP stimulated actions could lead to care system distortions. The specific concerns expressed by the ARC included:

- 1) The premiums paid in public institutions for nursing care (required by SNF regulations) were displacing needed incentives for improved programming in a "social rehabilitation" mode, reflecting the "developmental model."

- 2) There was nothing in the track record of the private proprietary nursing home industry that suggested that publicly purchased private care was intrinsically superior to publicly administered care of the same type for impaired persons.

- 3) The fiscal pressures then being felt by many states to put

state "front money" into upgrading their mental hospitals to meet the standards required to draw down Medicaid for their eligible populations in the over-age-65 category was diverting funds from needed improvements in the state-sponsored facilities for the retarded. (Boggs, 1982)

As an alternative, the 1967 ICF legislation was offered as a flexible "nonmedical" model for residential services, under which, if it were to be made available in public as well as private residential settings, with meeting appropriate federal standards as a funding contingency, substantial improvements could be affected in the quality of care to mentally retarded people.

During the following November (1970), the Senate Finance Committee was preparing to mark up H.R. 17550, a massive piece of legislation, described on page 2 of the Senate Report (91-1431) as "the largest social insurance bill, in terms of dollars, that Congress has ever acted on...". While this report was being prepared, Messrs. Cohen (former Secretary of HEW) and Rader (head of Oklahoma's Department of Social and Rehabilitation Services) paid visits to Oklahoma's Senators Fred Harris (D), at the time a member of the Senate Finance Committee, and Henry Bellmon (R) to lobby for inclusion of a benefit for state institution residents. When the Committee reported H.R. 17550 with its amendments in December, a new Section 269(b) added intermediate care to the list of services fundable at state option under Medicaid, with a provision authorizing inclusion of public institutions for the retarded as ICFs under certain conditions. The text is reproduced here:

With respect to services furnished to individuals under age 65, the term "intermediate care facility" shall not include, except as provided in subsection (e), any public institution or distinct part thereof for mental diseases or mental defects. Clause (2) shall not apply to any such institution or distinct part thereof which meets the requirements of subsection (e).

(e) The term "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 —

(1) the primary purpose of such institution (or distinct part thereof) is to provide health or rehabilitative services

for mentally retarded individuals and which meet such standards as may be prescribed by the Secretary;

(2) the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and

(3) the State or political subdivision responsible for the operation of such institution has agreed that the non-Federal expenditures with respect to patients in such institution (or distinct part thereof) will not be reduced because of payments made under this title.

The Senate report states clearly: "The purpose here is to improve medical care and treatment of the mentally retarded rather than to simply substitute Federal dollars for State dollars." (p. 148).

Considering the many amendments added to H.R. 17550 by the Senate, it was not surprising that the House and Senate could not come to an agreement before the close of the 91st Congress. Thus, ICFs remained for another year under Title XI. When the new 92nd Congress convened, House Ways and Means chairman Wilbur Mills was determined to tackle welfare reform again: his intention was signaled by the number assigned to the Social Security Amendments bill—H.R. 1. As reported, H.R. 1 contained ICF provisions very similar to those included in the 1970 Senate bill (House Report 92-231, p. 112). H.R. 1 passed the House in June, 1971; by December it was apparent the Senate would again need more time to "work its will" on this landmark legislation.

Three provisions were selected with the consent of the Senate Finance Committee for expedited handling before the Christmas (1971) recess. One of these was the 1971 House (H.R. 1) language on intermediate care. This language was offered as an amendment to another pending bill, H.R. 10604, by the two senators from Oklahoma, with the support of Senator Long (D-Louisiana), chairman of the Senate Committee on Finance. The debate on this amendment, which actually consisted of its explanation by supporters, appears in the Congressional Record for December 4, 1971. Because it is sometimes quoted only

in excerpt, the entire relevant text is appended to this chapter. The conference committee concurred (with technical changes) and the final bill cleared both houses on December 14, was signed by President Nixon and became effective January 2, 1972.

P.L. 92-223 defined an intermediate care facility as:

an institution which

(1) is licensed under State law to provide, on a regular basis, health-related care and services

(2) meets such standards prescribed by the Secretary as he finds appropriate for the proper provision of such care, and

(3) meets such standards of safety and sanitation as are established under regulation of the Secretary in addition to those applicable to nursing homes under State law.

P.L. 92-223 further defines ICF to:

include services in a public institution (or distinct parts thereof for the mentally retarded or persons with related conditions IF

(1) the primary purpose of such institution is to provide health or rehabilitative services for mentally retarded individuals and which meet such standards as may be prescribed by the Secretary;

(2) the mentally retarded individual with respect to whom a request for payment is made under a plan approved under this title is receiving active treatment under such a program; and

(3) the state or political subdivision responsible for the operation of such institution has agreed that the non-federal expenditures with respect to patients in such institutions will not be reduced because of payments made under this title.

The last stipulation was subsequently amended by P.L. 92-603 to read:

(3) the State or political subdivision responsible for the operation of such institution has agreed that the non-federal expenditures in any calendar quarter prior to January 1, 1975, with respect to services furnished to patients in such institution (or distinct part thereof) in the State will not, because of payments made under this title, be reduced below the average amount expended for such services in such institution in the four quarters immediately preceding the quarter in which the State in which such institution is located elected to make such services available under its plan approved under this title.

No maintenance of effort clause has been operational since 1975.

Refinancing has in fact been in effect since that time, although the rapidly

increasing costs of public institution care would have made any maintenance of effort clause that was not indexed quickly meaningless. Some states have formally or informally utilized within the community that portion of their federal reimbursements which was not needed to cover the increased costs of compliance. In most states, however, reimbursements, when they arrived, reverted to the general treasury. In fact, it may well have been counterproductive to require states to maintain their aggregate level of expenditures in each institution inasmuch as their institutions' populations at the time this legislation was being considered had been on the decline for about 4 years (see Chapter 3) and many old units were scheduled for phaseout, a result generally regarded as desirable. Congressional Intent and Implications for Implementation

Based on the preceding overview of ICF-MR legislative history, and the discussion (explanation) of the amendment that is appended at the end of this chapter, it is reasonable to assume the following Congressional intent in enacting the ICF-MR benefit in 1971:

1. *The ICF-MR program would offer a major fiscal incentive for upgrading the quality of the physical environments and the care and habilitation being provided in public residential institutions.* A major objective of Congress in passing this legislation was to provide states with assistance in upgrading the quality of care in public institutions. Unlike the creation of the ICF-general in 1967, the ICF-MR facility was not conceptualized as a cost saving device, but instead as a means to expand Medicaid coverage to a specific population whose general quality of care at the time was notoriously poor (see Chapter 3). The ICF-MR program represented a national commitment to assist individual states in improving these facilities. This commitment was reflected both in the standards established for the program and also in the initial stipulation that federal funds

provided would augment, not supplant, state funds being spent prior to the certification of these facilities as ICF-MR providers. In other words, there was a general expectation, one that was only partially realized (see Chapter 7), that the funds available through FFP would be used largely to offset the increased costs of substantially improved care.

2. *The ICF-MR program would remove incentives for states to place mentally retarded residents in SNF or private ICF certified facilities solely to gain FFP.* A major factor stimulating Congressional consideration of legislation providing FFP for services that historically had been a major and virtually exclusive state responsibility was the increasing effort on the part of states to utilize existing authority for SNF and ICF care (intended primarily for the elderly) so as to secure FFP for care of retarded persons by certifying their public institutions as Skilled Nursing Facilities or by transferring their mentally retarded residents to private SNF or ICF nursing homes. The standards of these programs were generally found by intra-governmental audits to be ill-suited to providing appropriate service to mentally retarded persons. Public Law 92-223 attempted to neutralize these incentives for ICF and SNF placements by providing for retarded persons a distinctive type—or more properly, types—of care considered far more appropriate to their unique long-term care needs.

3. *The ICF-MR program would provide federal matching funds for a delivery model specifically designed to meet the specialized needs of mentally retarded persons in institutional settings.* It was not Congressional intent merely to provide a funding mechanism that would support the costs of non-nursing home residential care for mentally retarded people above the level of room and board. Section 1905 specifically establishes that the provision of "active treatment" is a primary criterion for obtaining FFP in the costs of the residential and habilitation programs made available to

mentally persons in institutions. Although the term was not well-defined in statute or in committee reports, it was and remains clear that participating facilities were expected to offer programs that included a major emphasis on training and habilitation. Congressional recognition that the needs of mentally retarded persons often differ significantly from those disabled elderly participants in other Medicaid long-term care programs is clear in statutory language stipulating that ICF-MRs need not focus primarily on health care as was the case for general ICFs. The amendment authorized federal matching under Medicaid "for care for the mentally retarded in public institutions which have the primary purpose of providing health or rehabilitative service" (Senate text and House Report 92-231, emphasis added). This provision in the statute was an innovative but largely unappreciated change in the purpose of the Medicaid program at the time of its enactment. It represented the first time under Medicaid that federal financial participation would be provided for institutional care that was not primarily medically oriented or only "health related."

Active treatment. Although the objective of authorizing treatment that was not primarily medical/nursing in nature may not have been fully understood throughout the Medical Services Administration, by State Medicaid agencies, or by the surveyors sent out by State health departments, it was not unintended by the Senate. There was a longstanding conviction among Senate staff that the federal government should not be financing "custodial" care. They were also guided by the breadth of Section 1901 of Title XIX—its original statement of purpose. As will be seen from this text, the words "health or rehabilitative services" were not chosen casually.

1901. For the purpose of enabling each State, as far as practicable under the conditions in such State, to furnish (1) medical assistance on behalf of families with dependent children and of aged, blind, or

disabled individuals, whose income and resources are insufficient to meet the cost of necessary medical services, and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care, there is hereby authorized to be appropriated for each fiscal year a sum sufficient to carry out the purposes of this title. The sums made available under this section shall be used for making payments to States which have submitted, and had approved by the Secretary of Health, Education, and Welfare, State plans for medical assistance*

The regulation writers took this into account when they defined "active meeting individual needs (see Medicare and Medicaid 1970, p. 100) and Senator Bellmon's "second condition" (Cong. Rec. December 4, 1971, p. S.20571) as the following text indicates:

S435.1009 Definitions relating to institutional status.

For purposes of FFP, the following definitions apply:

"Active treatment in institutions for the mentally retarded" requires the following:

(a) The individual's regular participation, in accordance with an individual plan of care, in professionally developed and supervised activities, experiences, or therapies.

(b) An individual written plan of care that sets forth measurable goals or objectives stated in terms of desirable behavior and that prescribes an integrated program of activities, experiences or therapies necessary for the individual to reach those goals or objectives. The overall purpose of the plan is to help the individual function at the greatest physical, intellectual, social, or vocational level he can presently or potentially achieve.

*The term "rehabilitation" (without a qualifying adjective) refers to restoration of lost function by any relevant means-medical, psychological, educational, or social. The term "habilitation" has come into use to describe the same comprehensive processes applied to persons disabled early in life before they have acquired the functional capacities they will need as adults. Since Section 1901 refers to "rehabilitation and other services to help...individuals attain or retain capability..." it is apparent that "habilitation" is an appropriate abbreviation of its intent and that coverage of comprehensive services (not limited to "medical") to alleviate disability was and remains part of the intent of Title XIX.

(c) An interdisciplinary professional evaluation that—

(1) Is completed, for a recipient, before admission to the institution but not more than 3 months before and, for an individual applying for Medicaid after admission, before the institution requests payment;

(2) Consists of complete medical, social and psychological diagnosis and evaluations and an evaluation of the individual's need for institutional care; and

(3) Is made by a physician, a social worker and other professionals, at least one of whom is a qualified mental retardation professional as defined in S442.401 of this subchapter.

(d) Reevaluation medically, socially, and psychologically at least annually by the staff involved in carrying out the resident's individual plan of care. This must include review of the individual's progress toward meeting the plan objectives, the appropriateness of the individual plan of care, assessment of his continuing need for institutional care, and consideration of alternate methods of care.

(e) An individual post institutional plan, as part of the individual plan of care, developed before discharge by a qualified mental retardation professional and other appropriate professionals. This must include provision for appropriate services, protective supervision, and other follow up services in the resident's new environment.

Eligibility of other than public facilities. The Congressional focus on public institutions, as noted earlier, represented an effort to create an appropriate benefit for persons who had not previously been targeted as the legitimate beneficiaries of any federal long-term care assistance program. Private facilities were not an issue, as they were already technically covered under the 1965 and 1967 amendments. Perhaps more important in this respect, at the time, public institutions were by far the predominant residential services mode for mentally retarded people. In fact, the 1969 survey of the National Master Facility Inventory found a total population of private mental retardation facilities of 24,350 versus a total population of 190,000 in state mental retardation facilities and another 31,000 mentally retarded people in state mental hospitals (Lakin, Bruininks, Doth, Hill and Hauber, 1982). What is more, few private facilities then existing were providing the intensity of care envisioned by Congress (or described in the subsequent standards) under this benefit.

At the same time, however, the statute did not specifically limit ICF-MR coverage, standards, or reimbursement to publicly owned facilities or even to comprehensive care ("total") institutions. The federal definition of "institution" which serves as the basis for facility participation in the ICF-MR program is the generic one which also covers the general ICF institution. This definition which appeared in the 1974 federal regulations (45 CFR Section 448.60(6)(1)), includes facilities serving "four or more persons in a single or multiple units." As already noted, it undoubtedly reflected recognition of the fact that there were many smaller facilities housing elderly or disabled persons which would be included in the ICF program, especially in rural areas.

Eligibility of small facilities. The inclusion of a definition including the "four or more bed" provision has been interpreted by some to mean that the original ICF-MR benefit was not proposed as much to target a specific locus of care (i.e., public facilities) as it was to stimulate a particular model of care (i.e., habilitation), which could be provided in any size of residential facility. On the record it seems that both factors were intended, i.e., in considering this provision Congress was focusing on extending Medicaid entitlements to improve the scandalously poor quality of care for mentally retarded persons in public institutions by making "habilitation" a sine qua non.

Congress was aware of—and apparently saw no need in 1971 to elaborate on—the use of small private arrangements for board and care pre-dating Medicaid. At a later time, after it was clear that a small as well as a large public facility could qualify under Title XIX, a further move was made to permit small non-medical (non-ICF) facilities under public auspices to receive residents eligible for public assistance without disqualifying them for their full SSI benefits. This was accomplished in 1976 by the addition of Section 1611(e)(1)(C) (P.L. 94-566). Residents of such facilities receiving SSI are, of course, also eligible for

"ambulatory" (non-institutional) Medicaid coverage.

By 1982 there were between three and four thousand persons with mental retardation in such small public non-ICFs, over twice the number (1,352) of residents of small public ICF-MRs (15 or less). The total number in group residences (facilities with full-time staff and training programs) of 15 or less was reported to be 42,018 of whom 9,714 were occupying beds in facilities certified for ICF-MR funding. Thus the "small group home" market was still dominated by private placements in non-ICF-certified facilities. This small group residence segment is now the fastest growing part of the residential care system for people who are retarded. The small ICF-MR component is also growing: in the two years following June 30, 1982, it grew from about 1,200 to about 1,770 facilities, although as discussed in Chapter 6, almost half (45%) of this total growth took place in New York State. There is also evidence that this growth has since substantially abated in those states with the largest small ICF-MR programs (in part through the use of the Section 2176 waiver).

Summary. Congress intended to promote through the establishment of the ICF-MR benefit **high quality**, habilitative residential programs for mentally retarded people. The instrument for such programs in 1971 was seen as the public institution, but the development of standards that permit small facilities to translate the original Congressional intent into contemporary standards of appropriate, high quality, and habilitatively oriented programs (see Chapter 3) seems clearly warranted. The equal inclusion of the growing number of private facilities under standards higher than the pre-existing standards for "general" ICFs seems equally important, because, in the absence of participation in the ICF-MR program, such facilities would be eligible to participate in the ICF-general program at an equal rate of FFP, but in most cases at considerably reduced standards of care for their mentally retarded residents.

Historical Development of ICF-MR Regulations

Just a month after the effective date of Public Law 92-223 John Twiname, Commissioner of the Social and Rehabilitation Service (SRS) issued a press release announcing the availability of intermediate care services under the new law and stating that all existing intermediate care facilities would be, for the time being at least, grandfathered in under the pre-existing regulations. There were at the time 32 states with programs funded under Section 1121. In 1971, the last year before transfer, \$8.3 million was expended for intermediate care; in fiscal year 1972 \$9.3 million was reported. The \$1.3 million increase was more than offset by a \$2.7 million decrease in SNF claims. ICF-MR expenditures were not tabulated separately until 1973.

An examination of the pre-existing regulations shows that they were "health related" even before transfer. Interim regulations had been published in the Federal Register of September 12, 1968 (33 F.R. 12925) with final regulations appearing on June 24, 1969 (34 F.R. 9782). The final regulations include state plan requirements for "consultation and working relationships" with the State agency responsible for mental retardation. Some additional modifications appeared on June 10th, 1970 (35 F.R. 8990). Taken together, these were the basis for the rules eventually issued for the "ICF-general" under Title XIX. As had been indicated during the Congressional consideration of the ICF transfer, more importance was placed on making the medically needy eligible than on programmatic changes for elderly/disabled populations.

In the initial stages of developing draft regulations specifically for mental retardation facilities (which were not finalized until January 1974) most of the debate within the Department of Health, Education and Welfare focused on the specific environmental and programmatic demands that should be placed on institutions by the regulations. A March 1972 set of issue papers from the Office of Social and Rehabilitation Services (SRS) outlined three basic choices regarding

the standards for ICF-MR participation: 1) to establish relatively low standards focusing primarily on basic safety and sanitation conditions that would permit most existing institutions to participate in the program; 2) to establish a moderately demanding set of minimum requirements for initial participation with the requirements for continued participation increasing over a phase-in period; and 3) to establish the relatively high standards of the Accreditation Council for Facilities for the Mentally Retarded (ACF-MR) or similarly demanding standards as a condition of initial participation. SRS recommended Alternative #2 be accepted and be the basis of the proposed regulations for the programs.

The Secretary eventually concurred with this recommendation and in March 1973 proposed regulations establishing what was seen by SRS as the moderate position with respect to standards for initial ICF-MR program participation. It permitted initial compliance to what was considered the minimum acceptable set of facility and program standards with the requirement that participating facilities would be required to meet ACF-MR standards by July 1, 1976. While considerable support was evident among consumer and advocate groups (most notably, the National Association for Retarded Citizens), a number of states were highly critical of the standards, which they contended were too demanding, too costly and/or too rigid and which provided a period to achieve final compliance that was too short.

In response to this criticism an alternative draft of regulations that presented the ACF-MR standards simply as guidelines rather than as explicit standards was circulated within the federal bureaucracy during the summer of 1973. This draft not only met substantial opposition within DHEW, but was also highly criticized by the Department of Justice which claimed that the "watered down" ICF-MR standards would not even require the quality of care that the Wyatt v. Stickney (1972) case, in which the Department of Justice participated as amicus curiae, established as minimally adequate under the Constitution. Therefore, the final

version of the regulations, published in January 1974 was much like the March 1973 proposed regulations. The most notable difference was that published regulations were an abbreviated version of the ACF-MR standards, whereas the initially proposed regulations had specifically referred to and cross-referenced the ACF-MR standards.

Over the course of the next ten years, several policy issues arose concerning the interpretation of and/or limitations of these original ICF-MR regulations. These issues involved revision of the original compliance deadlines for public facilities, certification of small facilities as ICF-MR providers, the medical versus social orientation of the standards, coverage of day habilitation and case management services, the performance of independent professional reviews, and others. Of these, the three most pervasive issues were 1) compliance deadlines for various life safety, living, dining, and therapy area requirements; 2) the degree to which authority and support was found in the regulations and passed on through HCFA regional offices for the development of small ICF-MR facilities; and 3) the medical orientation of certain regulatory provisions. Preceding the discussion of these issues, a summary is provided of the nature of the standards established in regulation for the ICF-MR program (42 CFR 400-516; 43 CFR 45233; as authorized in Sec. 1102 of the Social Security Act, 49 Stat. 647 [42 U.S.C. 1302]). In it, the major features that define the ICF-MR level of care are presented under a number of concrete requirements placed on participating institutions. The reader familiar with the specific content of the ICF-MR facility and program requirements, may wish to skip to page 42, "Compliance Deadlines." Policies and Procedures for ICF-MR Facilities

The regulations that were issued for the ICF-MR program in January 1974 established over one hundred specific standards with which participating facilities were expected to comply. These are described below under general categories of service and administration.

Authorization and planning of care and treatment. Before an ICF-MR certified facility receives reimbursement for the cost of services to an individual under Title XIX, an interdisciplinary professional team must confirm that the individual needs intermediate care or show that plans to provide a more suitable alternative are being undertaken. This authorization *of services is intended to confirm that the resident needs not only 1) board and room services, but also 2) a* planned program of care and supervision on a continuous 24-hour-a-day basis. At the federal level, no guidelines have ever been developed with respect to the nature of client conditions that might be expected to require both 1 and 2 as opposed to 1 only (states are given complete control over and vary widely in the nature and numbers of people authorized for ICF-MR services). In addition to continuous supervision, unlike board and care facilities, the ICF-MR facility was required *to provide "active treatment."*

The required elements of active treatment as contained in the ICF-MR regulations (42 CFR 435.1009) are presented on pages 1-26. In summary they include:

- (a) ...[R]egular participation, in accordance with an individual plan of care, in professionally developed activities, experiences, or therapies;
- (b) An individual written plan...[with] measurable goals... [prescribing] an integrated program...to reach those goals...to help the individual function at the greatest...level he can...;
- (c) An interdisciplinary professional evaluation;
- (d) Reevaluation...at least annually...;
- (e) An individual post institutional plan...

Resident protections. ICF-MR facilities are required to certify through their interdisciplinary professional team that residents admitted are persons whose needs they can meet. In addition, the facility must also have a written policy regarding the rights of residents (e.g., to privacy, property and association), and

rules for the control, training and discipline of residents, including for controlling and monitoring the use of physical restraints and the use of punishment. Facilities must keep a written record of residents' personal possessions and of financial assets received by or deposited with the facility and for all disbursements made at the request of or on behalf of residents. Facilities must maintain on all residents at least the following records relevant to their well-being: documents regarding residents' developmental and medical history; documents regarding legal status; copies of individual plans of care including plans for post institutional care; and records authorizing physical restraints and aversive (punishing) behavior modification techniques, including justification for their use, duration of their application and methods of monitoring their use.

All ICF-MR facilities must be certified by state Medicaid agencies as having met all applicable health standards. The facility must also meet the institutional requirements of the 1967 Life Safety Code of the National Fire Protection Association, although exceptions have been made for facilities of 15 beds or less, permitting application of the lodgings or rooming house standards of the Life Safety Code, provided all residents are certified as ambulatory and "capable of following directions and taking appropriate action for self-preservation." In addition, specific provisions of the Life Safety Code may be waived for specified periods of time if the agency responsible for monitoring compliance is convinced that "the waiver would not adversely affect the health and safety of the residents" and if "rigid application of specific provision would result in unreasonable hardship for the ICF-MR." Facilities must maintain a formal safety plan and carry out organized evacuation drills at least quarterly. They must also maintain records that document that the facility is in "strict compliance" with relevant sanitation, health, and environmental codes.

ICF-MR facilities must provide residents three planned meals per day at normal meal times under prescribed conditions governing storage, preparation, and

service of food. It must also provide residents with appropriate training to improve their independent eating skills. Records of meals actually served must be kept by the facility for a least 30 days. Facilities must have personnel competent to direct their food and nutritional service; if facilities have 20 or more beds their menus must be planned by a licensed nutritionist.

Facilities must have formal arrangements with a licensed pharmacist for dispensing drugs and biologicals, and with registered nurses for reviewing residents' medications monthly and notifying a physician when changes appear to be in order. In larger facilities, a registered nurse must supervise the facility's health services, but in ICF-MRs with 15 beds or less this requirement may be waived when a physician certifies that the residents are not in need of constant nursing services. Smaller facilities may contract with registered nurses or with health clinics to visit as required to care for minor illnesses. In addition, each facility must maintain a written transfer agreement with a local hospital that is near the facility to assure rapid access to appropriate medical care in the event of emergencies or in the event that hospitalization is required.

Administrative policies. ICF-MR facilities are required to have a written description of their philosophy and goals and objectives for residents that is available *to the public*. *Facilities are required to develop policy manuals and to make them available to all staff members whose areas of responsibility they cover.* Facilities are required to have a governing body which exercises general direction, formulates facility policy, and establishes appropriate staff qualifications.

Facilities must develop and make available a summary of relevant regulations and procedures governing the admission and release of residents. Such policies must minimally allow for admitting only residents who have undergone a comprehensive evaluation covering physical, emotional, social, and cognitive factors and for following-up within one month of admission with a case review to develop a program plan. They must include procedures for assessing the

advisability of, developing plans for, and facilitating the release of residents.

An ICF-MR's "chief administrative officer" (director) may be licensed as a nursing home administrator or a "qualified mental retardation professional" (QMRP). A person qualifies as a QMRP if in addition to at least one year of specialized training or experience in working with mentally retarded people, he/she is:

- (1) a psychologist with a master's degree
- (2) a licensed physician;
- (3) an educator with a degree in education;
- (4) a social worker with a bachelors degree in social work or a bachelors degree in some other field plus three years of social work experience;
- (5) a physical or occupational therapist;
- (6) a speech pathologist or audiologist;
- (7) a registered nurse;
- (8) a therapeutic recreation specialist who is a graduate of an accredited program; or
- (9) a certified rehabilitation counselor.

Resident living. Because the ICF-MR legislation was intended both to aid in the amelioration of the intolerably substandard living conditions existing in many state institutions at the time of its passage and to ensure sound habilitation programs for residents of those facilities, many of the regulations governing the program focus on the physical and habilitative qualities of these environments. Established standards include that residents should not have periods of unscheduled time longer than 3 hours, yet should have adequate free time for individual and group activities. Standards specify the need for outdoor activity and proscribe the most blatant forms of "warehousing" of the most severely impaired people by requiring that multiply handicapped and nonambulatory residents spend a major portion of their waking day out of bed with ample

opportunities to leave the sleeping area, to engage in activity and exercise periods and to move about.

Grouping and organization of living units. ICF-MR regulations stipulate that residents of "grossly different ages, developmental levels, and social needs [must not be housed in] close physical or social proximity, unless such housing is planned to promote the growth and development of all those housed together." They also require that residents who are nonambulatory, deaf and/or blind, epileptic, or otherwise multiply handicapped must not be segregated on the basis on their handicaps alone, but be integrated with their peers of comparable social and intellectual development.

Resident-Living staff. Regulations provide specific standards for intensity of care in ICF-MR facilities. They require that "there shall be sufficient, appropriately qualified, and adequately trained personnel to conduct the resident-living program, in accordance with the standards specified in these regulations" and that "living unit staff must make care and development of the residents their primary responsibility. This includes training each resident in the activities of daily living and in the development of self-help and social skills." They further caution that the ICF-MR must insure that the staff are not diverted from their primary responsibilities by excessive housekeeping or clerical duties or other activities not related to resident care. In addition to these general standards, the regulations set specific standards for the overall staff-resident ratios that facilities are expected to maintain with clients of varying intensity of care requirements, "unless program needs justify otherwise:"

(A) *For* -units including children under the age of six years, severely and profoundly retarded, severely physically handicapped, and residents who are aggressive, assaultive, or security risks, or who manifest hyperactive or psychotic-like behavior, the overall ratio (allowing for five-day workweek plus holiday, vacation, and sick time) is 1 to 2;

(B) For units serving moderately retarded residents requiring habit training, the overall ratio is 1 to 2.5; and

(C) For units serving residents in vocational training programs and adults who work in sheltered employment stations, the overall ratio is 1 to 5.

Design of and equipment in living units. In response to the conditions of regimented group treatment, overcrowding and inadequate equipment that in large measure stimulated the creation of the ICF-MR program, regulations set specific standards on the conditions to be maintained in living units. These are intended to assure that facilities provide adequately for the "comfort and privacy" of residents. They include that:

bedrooms shall:

- (1) Be on or above street grade level;
- (2) Be outside rooms;
- (3) Be equipped with or located near adequate toilet and bathing facilities;
- (4) Accommodate no more than four residents unless a variance can be justified on the basis of meeting the program needs of the specific residents and is actually granted;
- (5) Provide at least 60 square feet per resident in multiple sleeping rooms, and not less than 80 square feet in single rooms.
- (6) Provide adequate storage space that is accessible to the resident for personal possessions and prosthetic equipment; and
- (7) Have access to clean linen and dirty linen storage for each unit.

In addition to the required space and location of bedrooms, the regulations stipulate that each resident shall be provided with a minimal set of furnishings and bedding, including:

- (1) A separate bed of proper size and height for the convenience of the resident;
- (2) A clean, comfortable mattress;
- (3) Bedding appropriate for weather and climate; and
- (4) Appropriate furniture, such as a chest of drawers, a table or desk, and an individual closet with clothes racks and shelves accessible to the resident.

The regulations also require that:

(1) Space shall be provided for equipment for daily out-of-bed activity for all residents not yet mobile, except those who have a short-term illness, or those very few for whom out-of-bed activity is a threat to life.

(2) Each occupied room has direct outside ventilation by means of windows, louvers, air conditioning, or mechanical ventilation;

(3) Each occupied room has at least one window;

(4) Floors have resilient, nonabrasive, and slip-resistant surfaces; and

(5) Temperature and humidity are maintained within a normal comfort range by heating, air conditioning, or other means and heating apparatus that does not constitute a burn hazard to the residents.

Toileting areas are required to have:

(1) Toilets, bathtubs, and showers that provide for individual privacy, unless specifically contraindicated by program needs;

(2) If the facility has physically handicapped residents, water closets and bathing and toileting appliances must be equipped for use by them; and

(3) Hot water at all taps to which controlled so that it does not exceed 100 degrees Fahrenheit.

Professional services. ICF-MR regulations stipulate that residents are to be provided with a variety of special services by employees on the staff of the facility or by persons with whom the facility contracts to provide those services. The required services include:

1. Dental services: facilities are responsible for comprehensive diagnostic and treatment services, including a complete oral examination within a month after the resident is admitted and at least annual reexaminations; facilities are also required to make arrangements to have emergency dental treatment available on a 24-hours, 7-day-a-week basis, and to provide education and training to residents and staff on oral hygiene.

2. Training and habilitation services: facilities are responsible for services "intended to aid the intellectual, sensor motor and affective development of the

resident," including individual evaluations of residents for the purposes of developing written goals and objectives, specific training to meet those goals and objectives, and a record of both.

3. Medical services: facilities are required to have physician and emergency medical services available on a 24-hour, 7-day-a-week basis, to include physicians' evaluations in the ongoing resident monitoring and program planning process, to reevaluate residents' physical condition at least annually.

4. Pharmacy services: facilities are required to maintain a pharmacy manual that establishes policies and procedures regarding pharmacy services, to maintain a formal arrangement for qualified pharmacy services, including emergency services, and to maintain a medications history on each resident.

5. Physical and occupation therapy: facilities are required to provide residents with the direct or indirect services of licensed physical and occupational therapists in developing, carrying out, and monitoring programs focused on enhancing residents' physical and daily living skills.

6. Speech pathology and audiology: facilities are required to provide the services of speech pathologists and audiologists including screening and assessment of all residents, and direct services to those residents who need them.

7. Psychological services: facilities are required to provide direct or indirect individual psychological assessment, treatment and consultation, if appropriate, by a psychologist with at least a masters degree in psychology.

8. Social services: facilities are required to provide the services of a social worker for the evaluation and counseling of residents, as appropriate, for the support of individuals' families, for referrals to and securing utilization of other community resources as appropriate, for participation in periodic reviews of program plans, and for planning community placement, discharge, and follow-up services.

9. Recreational services: facilities must provide organized recreation

activities for residents consistent with their needs and capabilities conducted by trained and/or experienced staff and to provide adequate recreational areas and equipment on the premises of the facility for carrying out such activities.

Record keeping. Facilities must maintain records on all residents. These must include personal information, pre-admission evaluations, reports of interdisciplinary team evaluations, relevant health and accident reports, records of the use of restraints and aversive behavioral therapies, and observations regarding the resident's overall progress, and so forth. All information is to be maintained confidentially in facilities' central record areas so that they are easily accessible to staff members. The facilities must provide adequate documentation of their purchasing process and have an inventory control system which assures that adequate stocks of food, medicine, and other necessary supplies are on hand.

Compliance with the Original Regulations

By adopting the essentials of the ACF-MR A-level standards as the minimum federal requirements for the ICF-MR level of care, the Department of Health, Education, and Welfare assured that most public facilities would have to undergo significant, if not massive, changes to plant and program to become certified as ICF-MR providers. In all, federal regulations (42 CFR 442, subpart G) established 116 individual standards that ICF-MRs were expected to meet. However, because of substantial demands placed on institutions in achieving compliance, the Secretary of the Department of Health, Education, and Welfare decided to allow public residential facilities for mentally retarded people to phase into the ICF-MR program and, consequently, two sets of regulations were published in 1974. An interim set of regulations provided the minimum acceptable standards which a facility had to meet to receive FFP for services rendered to Medicaid recipients of ICF-MR care while program development and facility renovation was underway to meet the final ICF-MR regulations which were to become effective in March 1977. The extent to which the original compliance deadlines were adhered to (i.e., the

date from which the above standards were to be enforced), as well as the extent to which states have actually complied (have been compelled to comply) has had major effects on the residents of ICF-MR facilities in the past decade, at least in comparison with what the regulations originally promised. Examination of the relationship between state and federal governments with respect to compliance to the federal regulations also is the best avenue to understanding the extent of federal ability and resolve to actualize the federal standards in programs that are operated, administered, and monitored by state governments.

Redefinitions and delays in compliance deadlines. The detailed standards for final compliance that pertained to administrative policies and procedures, resident living, professional services and safety and sanitation represented a substantial departure from the existing situation in most state institutions. The most costly and controversial parts of the regulations, however, related to rooming standards. These regulations, which were based on existing standards for skilled nursing facilities, permitted not more than four beds to a room, although the interim regulations permitted 12. Converting dormitory wards into bedrooms for four persons became a major capital investment issue in the states. It also became a major inducement to the depopulation of public institutions in that the bedroom size requirement, which in addition to limits of four beds per room, required a minimum of 80 square feet per single occupant bedroom and 60 square feet per occupant in rooms with more than one occupant, could not be met in many institutions without either increasing their space or reducing their reduced resident populations. But given the existing physical plants within most state institutions, not only would populations have to be reduced, at the same time, substantial facility renovations would have to be undertaken as a prerequisite for future funding of the remaining residents.

It may be somewhat ironic that a sleeping space requirement for residents who did not typically spend the major part of their day in their bedrooms (at least in

comparison to the nursing home residents for whom the standard of four beds per room was originally established) would become such a considerable impetus for institutional depopulation and capital investment in public institutions. On the other hand, the excessive resident density and lack of privacy in sleeping areas was generally representative of the same conditions in aspects of public institution care. The new sleeping room standards notwithstanding, it also soon became apparent that state Medicaid agencies would frequently make use of their authority to allow variance from these standards on the grounds that assignment to sleeping rooms or wards with more than four persons was "in accordance with the program needs" of residents, a practice still commonly employed (see, for example, in Senate Hearing 98-1045, pp. 10-11, a report of the Senate Subcommittee on the Handicapped).

Because virtually all ICF-MRs were state-owned and operated in the early years of the program, legislative appropriations were required for renovation and new construction for almost all ICF-MR participating facilities. State borrowing to finance such capital costs was accepted, however, because the costs of interest and amortization could be built into the reimbursed expenses of future occupants, and therefore cost-shared with the federal government. In addition, other states decided to upgrade limited sections (distinct parts) of existing facilities and/or to phase out all or parts of certain existing public facilities and relocate clients in other settings.

1977 revisions of the original compliance deadlines. More than a year before the March 1977 deadline for full compliance was upon them, states, through the National Association of Coordinators of State Programs for the Mentally Retarded (NACSPMR) began to express concern that they would not be able to complete the physical renovations or new construction to meet the final standards. A number of reasons were cited for the difficulty. Some of the states that had planned to phase out certain beds and place the residents in alternative care settings were

claiming that the alternative settings were not developing quickly enough to meet the phase out goals. Some states which planned to build new facilities said they had encountered delays in the appropriations process that would prevent timely compliance. Other states indicated that available funding would simply be insufficient to achieve compliance with structural and staffing standards. Other states argued that the personnel required to meet the standards were unavailable to them. Although most of these problems were intra-state problems (e.g., state legislatures not appropriating the funds necessary to bring institutions onto compliance), state human services officials presented them as, and felt them to be, uncontrollable impediments to meeting compliance deadlines.

Because of the problems impeding states' compliance, NACSPMR recommended in January 1976 that the March 1977 deadlines be set back. The compliance problems were so apparent that the Directors of the Regional Offices of Long Term Care Enforcement estimated in 1976 that 40 of the 177 facilities receiving ICF-MR reimbursement at that time would probably not be able to meet the standards to become effective in March 1977. Nevertheless, states badly wanted and, indeed, appeared to feel entitled to the federal matching funds even while admitting that the care they were providing was not in compliance with federal standards.

After accepting a task force report from representatives of the National Governors' Conference (now Association), National Conference of State Legislatures, National Association of Counties and the National League of Cities arguing for a prolonged period in which to achieve full compliance, and another task force report from the National Association of Retarded Citizens arguing for maintenance of the established standards, and after consulting with a range of other government and advocacy groups in the summer of 1976, an interagency work group was formed within DHEW to propose a departmental policy with respect to compliance. That policy, expressed in a September 22, 1976 letter from

Under Secretary Lynch to Governor Andrus, Chairman of the National Governors' Conference, indicated that the Department would maintain in principle the March 1977 deadline, but it would permit continued Medicaid participation by facilities that showed substantial progress toward meeting those standards and the resource commitments necessary to continue the progress.

A "Notice of Proposed Rule Making" reflecting this and other proposed modifications of the compliance deadlines and standards was published (45 CFR 249.13) in the January 18, 1977 Federal Register. Generally advocacy groups (notably the NARC) opposed "watering down" the original requirements of compliance to receive FFP while state government representatives (notably the NGC) requested even greater flexibility in the final standards, including an extension of a final deadline for compliance to 1982.

The final regulations that were issued on June 3, 1977 reflected many of the recommendations of the state government officials. These regulations provided that the State Survey Agency could certify an ICF-MR with deficiencies in the areas of Life Safety and environmental conditions even though correction of the deficiencies under the facility's plan of correction would take more than 12 months to complete. The regulations required that the plan of action provide for completion of corrections by July 18, 1980. However, if at the time of the first survey after July 17, 1977 the facility was unable to develop a plan for completion of corrections by July 18, 1980, the State Survey Agency could request that the Secretary approve a plan to complete correction by July 18, 1982, if certain additional requirements were met. In order for a plan of correction to qualify, requests for extension had to be predicated on 1) renovations or structural changes or 2) phasing out all or part of the ICF-MR. The revised regulations also gave the States permission to request an extension of up to one year, after July 17, 1977, to bring facilities in compliance with minimum direct care staffing ratios. (A national ARC Governmental Affairs Office state survey

[1978] following the July 1978 deadline found that in 38 states with ICF-MR programs 33 states had surveyed compliance. Of 32 states documenting the findings of compliance reviews, institutions in 6 states were noted to be out of compliance with direct care staffing regulations.)

State responses to federal extension of ICF-MR standards. The majority of states responded to the 1977 regulations by moving forward with their construction, renovation, or phase out plans. According to a survey conducted by the National Association of State Mental Retardation Program Directors, over the three fiscal years covered by the study (July 1, 1977 to June 30, 1980) the fifty responding jurisdictions reported actual and projected state appropriations totalling almost one billion dollars (Gettings & Mitchell, 1980). Actual and projected capital appropriations varied considerable from state to state, with five states (CA, MI, NJ, NY, and OH) accounting for over one-half of the total outlays reported for the three year period. Per capita outlays for institutional construction/renovation projects during the reporting period ranged from a high of \$24,205 per institution resident in Washington state to a low of \$404 in Rhode Island. The national median per capita outlay for the three year period was \$5,460 per resident.

Most of the state capital appropriations during the period (82.7%) were earmarked for construction and renovation projects on the grounds of existing state-operated residential facilities. In fact, two-thirds (33) of the 50 responding jurisdictions reported that their entire FY 1977-80 capital improvement budgets for state institutional care of mentally retarded persons would be obligated for such renovation projects. Twenty-six of the thirty-nine jurisdictions able to provide exact expenditure figures estimated that three-fourths or more of their capital outlays during the three-year period would be devoted to projects specifically targeted on improvements needed to bring institutions into compliance with federal ICF-MR standards.

1981 regulations. As a result of these efforts on the part of states, the Health Care Financing Administration, which administered the ICF-MR program, was apparently confident that most states would complete their plans of correction prior to July 18, 1980. In reality, at that time at least 36 facilities representing 11,000 beds (ten percent of all ICF-MR beds) were estimated to still be out of compliance. These facilities represented about \$50 million in Medicaid FFP. On January 6, 1981 HCFA issued another regulation which permitted the state survey agency to request the Secretary of HHS to authorize approval for certification of a facility which was unable to complete all needed corrections by July 18, 1980 and which had not already applied for an extension to 1982. In order to have this one year extension approved, the facility would be required to demonstrate that it had made substantial progress toward successful completion of its plans of correction. "Substantial progress" was defined in the regulations as follows:

For corrections involving construction or renovation, the facility would be required to provide documentation of a supervised contractor or architect that the facility had completed at least 25 percent of the work under the plan of correction by July 18, 1980 and that construction would be complete within one year after the survey.

For corrections involving the phasing out of all or part of a facility, the ICF-MR would be required to provide documentation that the phase out program was at least 25 percent complete on July 18, 1980. In addition, the state survey agency was required to find that the facility could complete the plan within one year after the survey.

In many states, the most blatantly substandard facilities had been those that were targeted to be upgraded or phased out first. As this work progressed some state mental retardation agencies argued they were without adequate appropriations to bring other institutions into compliance by the July 1980 deadline. For some of these facilities, states had neither requested an extension to 1982 nor could they reasonably be expected to meet the 25% completion schedule. At the request of states in this situation, arguing it would be hard to justify penalizing states simply for lacking the foresight to see that achieving compliance

would take 5 years instead of 3, when other states had exercised the option to request five years to achieve compliance, HCFA permitted states to request another extension on the basis of the aggregate progress a state had made. This request would be granted as long as all the work in all the affected buildings was to be completed within one year and the state had completed 25% of the work needed to reach compliance with the provisions of the regulations.

1982 extended phase out regulations. Soon after publication of the January 1981 regulations, New York and Pennsylvania informed the Office of Management and Budget, and the Secretary of Health and Human Services that a regulation which allowed extended phase-out of beds would permit them to defer construction and renovations and achieve significant cost savings. As it happened, this proposal was similar to a March 1979 recommendation from the then HEW Deinstitutionalization Task Force to HCFA to clarify its ICF-MR standards for participation to provide a liberal waiver policy on the requirement for compliance with certain conditions by July 18, 1980. The Task Force recommended that HCFA grant waivers of the applicable standards where a plan of correction provides for (1) relocation of clients in least restrictive care settings and (2) phasing down institutions within a definite time frame, on the condition that petitioning states could show concrete evidence of a bona fide effort to allocate budgets or to propose state legislation to fund what was embodied in the plan of correction. The Department of Health and Human Services ultimately agreed to the concept of an extended phase out option for ICF-MRs, and issued a proposed regulation on August 1, 1981 that was designed to stimulate an overall reduction in the number of certified beds in large residential facilities while forestalling further capital expenditures for the renovation of existing facilities or the construction of new units where an extended phase out of units was feasible. The regulations, as proposed, extended the Secretary's authority to approve a facility's plan of correction if it included:

1. A schedule of increased phase out goals, which means that the facility is willing to add already certified beds to those previously scheduled for phase out;

2. Phase out targets set at six-month intervals, a time frame which was chosen that would give the facility sufficient opportunity to achieve targeted goals before it would be subject to a loss of federal funds for failure to meet targeted goals;

3. An overall period of time for the completion of the plan, not to exceed five years from the effective date of the final rule, such time period to be negotiated with the Regional Office based upon the size of the facility, the extent of the phase out to be achieved, and the facility's prior phase-out performance. The greater the distance the facility is from its original goals and the less the facility is willing to add to its phase out targets, the less flexibility in additional time will be provided;

4. Documentation that the facility has already met at least 25% of its original plan of correction;

5. Assurances that no new residents never before classified for ICF-MR level of care will be admitted to units slated to be phased out and that the health and safety of the residents in units slated to be phased out are not endangered.

The rule specified that non-certifiable beds could not be added to the revised plans of correction. This provision would prevent the inclusion of beds not previously certifiable in order to gain FFP while phasing them out.

By the end of 1982 the compliance deadline issue had technically died. However, the tendency of federal administrations to be relatively acquiescent to the pressures of states to maintain FFP as they undertook, at their own pace, the process of complying to the official standards established a relatively low expectation of federal enforcement of this program, an expectation that has been dramatically altered by increased numbers of surveys, audits, and accompanying losses of FFP in Fiscal Year 1985. The following paragraphs summarize federal enforcement activities.

Extent of compliance to ICF-MR standards. During the long, drawn out period throughout which states were continually given extensions of earlier deadlines for compliance with ICF-MR regulations in order to retain FFP, there

was without doubt substantial general improvement made in the residential and habilitative program components of state institutions (see, for example, Inspector General, 1981). However, it is not clear to what extent this accomplishment is directly attributable to states' efforts to comply with ICF-MR regulations rather than to continuation of significant state efforts to improve institutional care that actually preceded the authorization of the ICF-MR benefit (partly due to court-based efforts to extend Constitutional protections to inmates of public institutions, and to mounting public and professional pressure to correct the national scandal of state institution care). Even with whatever improvements may have been realized through the ICF-MR program in its first decade, Court cases and their threat, which led a number of settlements, were very major factors in requiring improved quality of many specific institutions and the expectation for improved quality in all institutions (see Chapter 3). It is certainly not irrelevant to consideration of the efforts of the ICF-MR program to note that those specific state institutions which through legal redress have been required in the past decade to substantially improve their conditions of residence and habilitation were in most cases ICF-MR participating institutions (Beatrice, Belcherton, Cambridge, Fernald, Laconia, Ladd, Mansfield, Monson, Pennhurst, Plymouth, and Willowbrook, to name just a few).

Because of this tenuous relationship between ICF-MR program participation and the provision of constitutionally tolerable levels of care, habilitation, and freedom from undue restraint, an issue that has been increasingly attended to recently is whether states are even now meeting ICF-MR regulations, years after the original and even the prolonged compliance deadlines. Indeed there is some question about whether real compliance should be expected when the provider of the service is also assigned primary responsibility to monitor and certify that it meets the standards necessary to be reimbursed for it (the federal government does have a "look behind" authority, but until very recently has had inadequate

staff and apparently low commitment to carrying it out). As the Executive Director (Roos) of the National ARC noted in a letter of November 11, 1980 to the Secretary (Harris) of Health and Human Services during the last of its (lost) debates with DHHS about another delay in compliance deadlines:

The pending decision on compliance deadlines represents [just] one aspect of the long-term care dilemma and should be in line with the Department's philosophies and plans in this area.... Our major concern then and now is the lack of enforcement by the Department of its program regulations. In 1974 the Department published regulations governing the ICF-MR program. In many instances enforcement of these regulations has yet to occur. Given the lack of enforcement we question the meaningfulness of debating deadlines for compliance.

The extent to which ICF-MR certified state institutions have actually complied with ICF-MR regulations, even after a decade to do so, appears to be remarkably low (Medicare and Medicaid Guide, 1984; Senate Hearing 98-1045, Services for Mentally Retarded Persons, 1984). According to a review by Taylor et al. (1981) of the contents of 44 deficiency reports of Medicaid survey teams in 23 states, the comprehensiveness of state surveys of their own facilities is low (a quarter of all were judged "adequate" or "marginally adequate") and the plans of correction are "strikingly inadequate and empty" and "often propose vague bureaucratic policies and procedures to correct concrete deficiencies."

In May 1983 Secretary Heckler of Health and Human Services was made a party to consolidated suits that had been brought against five ICF-MR certified state institutions in Massachusetts. She was ordered to visit and inspect each facility and to advise the court as to whether the facilities were complying with ICF-MR standards, as they had agreed to do as part of a consent decree in 1977. Secretary Heckler observed the facilities to be clearly out of compliance (Medicare and Medicaid Guide, p. 9619). In 1984 Secretary Heckler testified before a hearing of the Senate Subcommittee on the Handicapped (Senate Hearing 98-1045) reporting on the findings of federal survey teams' "look behind" inspections of 17 state certified facilities. She noted that "the majority did not meet requirements

concerning active treatment," and that "some were not meeting sanitation and physical environment standards. Deficiencies relating to heating, ventilation, cleanliness, and general maintenance were common. Some facilities were seriously deficient in their dispensing and/or monitoring of drugs administered to clients" (pp. 33-34). Heckler's testimony was supported with a detailed chart of the deficiencies in 9 of the 17 facilities inspected, which showed that on 82 specific standards these 9 facilities averaged deficiencies on over one-third.

In addition to recent inspection reports supplied by the Secretary of Health and Human Services regarding the general extent to which institutions are complying to ICF-MR regulations, the Senate Subcommittee on the Handicapped also issued a 1984 report based on the inspection of 7 large (400 or more beds) ICF-MR certified state institutions (Senate Hearing 98-1045, pp. 2-22). This report noted a number of conditions that violated the letter and the general purposes that were contained in the ICF-MR legislation. Among these were: inadequate privacy and access to residents' own possessions, unjustifiable waivers of the sleeping room standards, failure to provide any or appropriate active treatment, poor quality and appropriateness of clothing, no access to recreation and leisure materials, and reliance on chemicals vs. behavioral training to modify behavior. The Subcommittee on the Handicapped report also noted, as have most analyses of the ICF-MR program, that quality assurances processes simply are not working.

Based on the evidence brought forth in courts, ethnographic research, and, most recently, federal government inspections, the conclusion that the compliance processes are not working cannot be credibly refuted. Clearly the most obvious problem with respect to these inadequacies is that Medicaid law vests states with the responsibility for monitoring compliance with the standards of the ICF-MR program, which for most ICF-MR recipients they themselves provide.

In fulfilling the monitoring responsibility for nursing homes (SNF and ICF) states have a much less direct vested interest. In the vast majority of all cases

these facilities are privately operated and the states, through their survey agencies, can retain a reasonably detached perspective on regulatory compliance by providers. However, when the ICF-MR program was created, no new monitoring processes were created to compensate for the obvious conflict of interest inherent in having states operate as both the providers and the monitors of their own programs. The problem was exacerbated by the fact that surveyors, who originally monitored Medicaid certified nursing homes, often did not have experience with programs for mentally retarded people that might have compensated for some of the inherent inadequacies of the survey process. Ironically, increased efforts to create within survey agencies improved capacity to monitor compliance with ICF-MR regulations has more closely paralleled the growth of smaller private facilities, than the documentation of numerous inadequacies of state ICF-MR facilities.

However, it is by now obvious that increased sophistication on the part of the surveyors has not substantially compensated for the structural inadequacy of permitting states to monitor their own programs. One possible remedy for the existing problem would be placing primary, not just ultimate, responsibility for monitoring state ICF-MR facilities in federal agencies, like the regional HCFA offices, or to establish other independent bodies for that purpose. Only such independence can make assurances that facilities are in compliance, or undertaking real action to become so. (Very little is known of the level of compliance to regulations of private ICF-MR facilities. Recent federal audits of all types of ICF-MR facilities should soon provide some assessment of private facility compliance.)

Could the process of complying with regulations have created undesirable effects? Another issue with respect to the effects of the ICF-MR compliance requirements is not whether they have been adhered to, but whether states' efforts and expenditures to do so have actually had neutral or negative effects on the

overall quality of care for mentally retarded people, as "quality" is perceived in the 1980s. The question is whether the general quality of residential care available to mentally retarded people today might be better had not ICF-MR reimbursement been available to defray the costs of responding to the pressures for improved institutional care through investing in those institutions. Perhaps states would have more quickly and comprehensively responded to the inadequacies of institutions by establishing community-based programs as alternatives if there had not been such a readily available and apparently cost-beneficial means of recouping large investments in institutions through Medicaid. As noted in Chapter 6, no data will ever be able to adequately respond directly to this question and the indirectly relevant data (e.g., comparisons of deinstitutionalization rates in states in relationship to institutional investments, comparisons of institutional populations in states with and without ICF-MR certified state institutions) is inconclusive. Recognition of Community-Based ICF-MR Providers

A consistent controversy in the development of the ICF-MR program has been the extent to which it has been centered in institutions and the extent to which its standards and FFP were transferable to community-based ICF-MR providers. As previously discussed, the ICF-MR benefit was not originally intended to be the comprehensive funding mechanism for entire residential care systems, but was envisioned by Congress to improve the conditions of care and habilitation of mentally retarded persons who "because of their mental and/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" (House Report 92-290).

The ICF-MR program, like all other long term care institutional benefits under Medicaid, requires operators of ICF-MR facilities to assume responsibility for all the needs of residents. This total responsibility based on the total institution model outlined in the ICF-MR regulations was generally perceived to

be inconsistent with the development of smaller, community-based programs, with their use of multiple agencies and services to provide an individual's complete program. Total institutional responsibility was further reinforced by the Medicaid funding mechanism, which through its vendor arrangement established that the flow of funds would be controlled by the facility, not the resident or by an outside agent—an administrative arrangement that was at substantial variance with the evolving recognition of case management and other external program and advocacy agency reviews as critically important to the protection of mentally retarded people in residential facilities (see Chapter 4).

Because the ICF-MR statute and regulations as written were largely inconsistent with what have become the prevailing concepts of reasonable standards for residential and treatment programs and administrative practices in small facilities, they have been criticized for their bias toward large facilities. However, formal interpretation of the regulations suggests that there has always existed the authority to develop small ICF-MR facilities in the community. The definition of institution in the ICF-MR program is the same as that in the ICF program, of which ICF-MR is a specialized type. This definition, appearing in the original regulations implementing the 1971 amendments, provided: "For purposes of Federal financial participation... Institution means an establishment which furnishes (in single or multiple facilities) food and shelter to four or more persons unrelated to the proprietor, and, in addition, provides some treatment or services which meet some need beyond the basic provision of food and shelter" (45 CFR 448.60(b)(1)). Thus the regulations provided not only for large-scale aggregate facilities—the definition states clearly "four or more." One can, of course, merely speculate as to whether the size distinction that recognized small facilities was explicitly intended.

It was, however, clear that the regulations issued on January 17, 1974 supported the development of relatively small facilities. They delineated two

categories of ICF-MR—those housing 16 or more and those housing 15 or less. The specific size break at 15 or fewer residents was apparently an outgrowth of the 1967 Life Safety Code, which included modified provisions for facilities of fifteen beds or less. The regulations issued on January 17, 1974 govern ICF-MRs of all sizes in a single document. Most standards apply to both the large and small institutions, but there are several significant provisions that specifically permitted the types of flexibility necessary to make small ICF-MR facilities a viable option. These include that in facilities of 15 or fewer residents:

1. Nursing services need not be provided on a full-time basis if a physician certifies that the residents do not require professional nursing services and if these services can be arranged on an "as needed" basis for minor illnesses, injuries, etc;
2. Registered dietitians are not required;
3. Compliance with the less restrictive lodging or rooming house section of the 1967 Life Safety Code instead of the institutional occupancy provisions is adequate if all residents are ambulatory, capable of following directions, and take appropriate action for self-preservation under emergency conditions;
4. Reduced day staff coverage is permitted when residents are in extra-mural day programs of ongoing active treatment;
5. Facilities may be administered by a Qualified Mental Retardation Professional or by a licensed nursing home administrator;
6. Necessary professional services may be on a contracted basis as long as quality is assured; and if no residents need particular required available services (such as OT, PT, etc.) those services are not required. (This provision applies to all size facilities, but is particularly significant to the viabilities of the smaller facilities).

Despite these provisions recognizing and to some extent facilitating the development of ICF-MR facilities of from 4-15 residents, the development of

small community-based ICF-MR facilities has varied enormously across states. In 1977 over three-fourths of all private, small ICF-MR facilities (15 beds or less) were in Minnesota. In 1979 Allard and Toff (1981) estimated that 81 percent of all small ICF-MRs (15 bed or less) were located in only five states and about half of the certified small community facilities were still in the state of Minnesota. While some HHS Regions (e.g., Region V) had developed hundreds of small ICF-MR providers, other Regions (e.g., II and X) had none. This wide variation in state implementation reflected what some states and national organizations considered a failure of HCFA to delineate clear policy guidelines for the certification of small facilities as ICF-MR providers, a reluctance on the part of some regional agencies to promote the use of this alternative, and a lack of commitment within HCFA to promote the depopulation of large state institutions.

In response to continued complaints from the states that there was a need to clarify Departmental policy regarding the use of the ICF-MR program for small residences, in 1981 HCFA issued "Interpretive Guidelines for the Application of the 1977 Standards for Institutions for Intermediate Care Facilities for the Mentally Retarded Serving 15 or Fewer Persons." The purpose of these guidelines was to show how the existing ICF-MR regulations could be applied to facilities with 15 or fewer clients. The State Operations Manual on Provider Certification, in which these guidelines were published, indicated that the guidelines reflect "current philosophies and practices in assisting persons with mental retardation."

Introductory materials to the Guidelines indicate that "An effort has been made to interpret the standards for ICF-MRs in terms of facilities serving 15 or fewer persons within the framework of the principles of normalization, least restrictive environment, and the developmental model of program services delivery, including the interdisciplinary (and, to a large extent, Transdisciplinary) approach to intervention." (These concepts are described in Chapter 3.) But instead of providing a standard-by-standard translation of the ICF-MR regulations

as they would be expected to be met in small facilities, the guidelines approached the clarification of some of the many ambiguous issues regarding the smaller ICF-MR facility by providing options and examples. For instance, the regulations require that the preadmission evaluation be reviewed within one month after admission, but they do not make requirements regarding the factors to be considered. Obviously, the interpretive guidelines can be no more specific than the regulations on which they are based, but they do list 7 general areas of evaluation, indicating that these are merely suggestions and that an adequate evaluation need not include or be limited to any of these. In addition to their guidance by examples, the Interpretive Guidelines provide some general recommendations. For instance, they do not recommend a minimal number of hours considered desirable for the engagement of qualified consultants in program areas, but link the use of consultants to the specific circumstances of a facility and its residents.

In many ways these guidelines appear to suggest considerably more flexibility is provided to small ICF-MR facilities than to providers in large facilities. On the other hand, the regulations were clear that small facilities retained the responsibility to reflect the primary component of ICF-MR care, "active treatment." Prior to the issuance of the guidelines, confusion had been expressed about the active treatment requirements for a facility that desired to utilize extra-mural day services as a primary habilitation component. Questions arose regarding whether intra-facility active treatment programs would be required in addition to the professional services obtained through the outside programs or whether a somewhat more normalized situation would permit an individual to return to a relatively "unprogrammed" residential environment after a full day of day services. The Interpretive Guidelines promote a middle ground interpretation of the active treatment requirement for small facilities utilizing extra-mural habilitation programs, attempting to clarify ways in which the facility can

provide for the continuity of training by integrating its own program with that of an outside source and vice versa. The guidelines have by and large been considered to well describe the essentials of the ICF-MR level of care as it can be efficiently provided in small facilities.

Medical Oriented Requirements and Their Discordance with Evolving Standards of Appropriate Care

In addition to the controversies surrounding compliance issues and the shifting of Medicaid resources from institutional to community settings, since the inception of the ICF-MR program there has been considerable concern about the medical orientation of the program. The specific issue is whether its inclusion in and administration by a health care oriented agency focuses ICF-MR regulation and enforcement excessively toward medical and nursing services, at some cost to habilitation and/or cost-effectiveness. While this issue may well be one of substantially decreasing pertinence in recent years, it is still a common criticism and requires some attention in a discussion of the program and its regulations.

The medical orientation of ICF-MR facilities. The statute establishing the ICF-MR program authorized federal matching under Medicaid "for care for the mentally retarded in public institutions which have the primary purpose of providing health or rehabilitative services..." By so doing, the Congress in establishing the ICF-MR program clearly recognized that the needs of mentally retarded persons often differ from the needs of elderly nursing home residents. General ICFs are required to be health related facilities, but ICF-MRs are not so required. Provision was clearly made that retarded persons could be eligible for habilitation in an ICF-MR without demonstrating a primary health need.

Nonetheless, the ICF-MR program is a component of the medically-oriented Medicaid (Title XIX) program, and as such, many general requirements originally developed for and clearly more applicable to long term care services for elderly persons with chronic illnesses and disabilities have been undeniably superimposed

on ICF-MR services. It has been argued that these medical requirements add significant unnecessary costs to the program and may detract from the developmental orientation that is needed by mentally retarded clients. For example, a report prepared by the MR/DD Division in the state of Indiana (cited in Allard & Toff, 1980) seems to reflect the views of many state officials:

"Intermediate care facilities are primarily health care facilities and tend to be judged by medical standards which are irrelevant to the major needs of most developmentally-disabled people. For the most part medical/nursing needs of developmentally disabled persons can be met in the same ways that typical people meet their needs: by health education, adaptive health aids and equipment, private doctors and clinics, visiting nurses, private and public hospitals. For those very few individuals who need to actually live in a health facility full time, 24 hours a day, seven days week, adequate beds currently exist.

...The bottom line analysis reveals the fact that current ICF-MR regulations and standards are fundamentally the outcome of a series of compromises; unfortunately the compromises are of the rights and needs of people who have no voice in the compromise. These compromises have taken ICF-MR standards from being clearly and undisguised a totally medical type facility, to what might now best be referred to as a "pseudo-medical" facility, or at best non-specific facility which has strong medical tendencies..."

There is certainly considerable evidence to support a contention that presuming extensive medical-therapeutic needs of mentally retarded persons may not be a particularly valid criterion around which to structure the standards of ICF-MR care. For example, a 1979 national study of residents in long-term care facilities for mentally retarded people, including 1450 residents of ICF-MR certified facilities, found the vast majority of ICF-MR residents (over 80%) were reported to have no chronic health impairments. Less than a quarter had major physical disabilities (including cerebral palsy); less than 15% received physical therapy (unpublished data of the Center for Residential and Community Services; related data are presented in Chapter 5.) Yet, whether medical/nursing requirements are excessive for ICF-MR certified facilities obviously is only determinable on a case by case basis. Because the health care needs of public, as well as private facility residents vary so substantially, it would be beneficial if

individual facilities could establish health and therapeutic standards on an annual basis as determined by the assessed conditions of their clientele. Other examples of ICF-MR regulatory provisions that have demanded a degree of medical orientation that has been perceived to be both inappropriate and inefficient are cited below.

Recertification of clients' need for service every 60 days. Until 1981, in order to meet the utilization review regulations, a physician was required to recertify the need for continued care in the ICF-MR every 60 days. In response to the argument that such a requirement guards against over utilization of facilities offering primary medical care, it is illogical for mental retardation, which is a highly stable condition (particularly for those individuals for whom the ICF-MR level of care would not be inappropriately intense in the first place). HCFA has recently permitted an annual recertification, finally agreeing that no medical justification exists for more than annual recertification, because as Senator Bellmon noted in his discussion of the original legislation, mental retardation, per se, is not a condition that tends to respond rapidly to treatment. Even so, with the absence of standards regarding client conditions that are perceived to justify an ICF-MR level of care, recertification, whether bimonthly, annually, or decennially, has become largely a pro forma process of predetermined outcome. Recertification of need would be more useful if the process were guided by developmental and health standards governing ICF-MR eligibility and guidelines regarding how developmental/health related eligibility should be determined. Finally, of course, recertification of need should be performed by persons who are independent of the provider agency.

Medically oriented client and facility reviews. ICF-MR regulations also charge an independent professional review team with responsibility for determining the appropriateness of placement of individuals certified for care in ICF-MRs. The team must evaluate each resident's individual plan of care,

evaluations, progress notes, and so forth, at least annually to determine if ICF-MR placement is appropriate and if the facility is providing the care he/she needs. In many states, these reviews have tended to be highly medically oriented with major emphasis being placed on the residents' medical status and progress rather than on his or her developmental, emotional, social, and cognitive status and progress. Similarly, particularly in the early years of the program, facility surveyors often had experience solely in health care facilities. As a result, they tended to emphasize the health aspects of the regulations rather than the habilitative aspects. In its statement to a Senate hearing on the ICF-MR program in 1984 (Senate Hearing 98-1045, pp. 95-97) the American Health Care Association noted **that:**

For **ICF-MR** standards to be properly enforced, surveyors must be properly trained in all aspects of the program.... AHCA recommends that surveys and inspections be made by individuals trained in the specifics of the ICF-MR program.... The care delivered in an ICF-MR is more complex than care provided in a traditional ICF. Surveyors must be aware of this and should be able to judge the adequacy of specialized services, (pp. 95-96).

Recently there has been increased training of review teams and facility surveyors in mental retardation and other developmental disabilities and selection of reviewers/surveyors with appropriate backgrounds, but the problem still remains significant in many areas. It is, of course, important to note that this particular problem and many of the others discussed under this heading derive from how states exercise the latitude given to them in the regulations. Whether constringing that latitude or attempting to strengthen states' abilities to carry out review processes is the best policy is largely a political one, perhaps one deserving study.

Facility responsibility for complete service packages. ICF-MR regulations require a wide range of services. While they also state that some of those services are required only to the extent that they are needed by the residents, they place the responsibility on the facility to arrange appropriate services. Thus it is each residential facility's responsibility to assure that each resident receives the full

range of medical, habilitative, protective and support services of adequate quality as required by regulation, even though the facility itself may provide only residential services. While such a model befits the total institution care model, indeed is based on the presumption of it, such a management model is often inefficient, costly and inappropriate for small community-based facilities that have little control over many aspects of residents' total programs. As a result, some states have assigned responsibility for overseeing the delivery of residential habilitation and health services in a specific area to a public or quasi-public agency. According to Robert Gettings, Executive Director of the National Association of State Mental Retardation Program Directors, this approach has several advantages over the self-contained ICF-MR approach, in that such an agency can "a) permit the state to establish separate vendor arrangements on behalf of ICF-MR - eligible clients in the community; b) reinforce the principle of normalization by permitting the residents to receive their daytime programming through available community resources, rather than in the residential unit; c) permit the state to exercise greater day to day control over the cost and quality of services provided in the ICF-MR and d) constitutes the most economical approach to operating community based ICF-MR services since costly professional services can be centralized and deployed across the network of small residences, rather than being replicated in each facility" (Gettings, 1980). While total control of an individual's residential and habilitation program by a single provider agency may fit the diagnostic-prescriptive model of nursing facilities, it is inappropriate for programs developed in large measure to counter the abuses that have been so apparent in the closed systems of total institutions (Goffman, 1963).

Institution based case management presents a related problem. While ICF-MR regulations recognize the importance of a professional who oversees the implementation of the individual's program plan, supervises training and habilitation services, monitors the individual's progress and initiates review of

his/her plan of care, this role is largely defined for the total institution context. In community-based programs in which the components of the individual's program plan are dispersed across multiple agencies and delivery sites, an independent program agent is important to insure the appropriateness and cost-effectiveness of each individual's program. However, the ICF-MR regulations make no provision for such an independent program development and monitoring function. Interestingly, the Medicaid waiver provisions (see Chapter 6) do recognize the importance of such a role in providing community-based services. Of all waiver services requested for mentally retarded beneficiaries by the various states, case management has been the most frequently sought (only one of 29 states with approved mental retardation waivers as of April 1984 had not requested case management services). As Medicaid reimbursed residential services continue to be decentralized either through small community-based ICF-MRs or Medicaid waiver services, the entire Medicaid program would benefit from rules requiring independent external case management function capable of focusing on the quality, appropriateness and effectiveness of an individual's complete program.

Conclusion

By the very nature of its being the primary funding and regulatory force in the provision of long-term care for mentally retarded people, the ICF-MR program is controversial. The controversy about it is heightened by the fact that it was originally designed to reflect and promote the quality of a model of care, public institutions, that has since fallen increasingly into disfavor, irrespective of the relative quality. In large measure it is to the credit of those who labored in and out of government to develop the regulations for the program, that they had the foresight to create standards that required substantial upgrading of public institutions while still providing the flexibility to create alternatives to them. Had the original legislation been narrowly interpreted, it would have had a considerably more antithetical relationship to the development of community-

based residential care for mentally retarded people. However, the considerable flexibility built into the ICF-MR regulations has not always been sufficient to satisfy simultaneously the desires of states to continue to depopulate state institutions through developing community-based alternatives while maximizing FFP in their overall programs; nor have advocates been satisfied that the dominant financial force in the residential services system is sufficiently focused on promoting contemporary visions (i.e., 1985 as opposed to 1970 when the legislation was introduced) of high quality residential services.

Because of these concerns a number of alternative policies have been instituted or proposed to adapt the ICF-MR program to the 1980's and beyond. These proposals include the Medicaid 2176 waiver authority that permits states to offer alternative services to Medicaid eligible persons, who but for those services would be placed in or would remain in an ICF-MR certified facility. This program, which is conditioned by general requirements that states neither spend more Federal funds nor serve more individuals than they would have in its absence, and states' responses to it are described in Chapter 6.

Another proposal, introduced in the Senate in 1983, the Home and Community Living Amendments (to the Social Security Act), had two major provisions. The first would have phased out Medicaid funding of all but small residential placements for mentally retarded people over a 15 year period. The second major provision was to authorize a wide range of alternative services to persons with mental retardation and other developmental or fortuitous impairments to independent functioning, without restricting the number of potential beneficiaries to the number of current or projected ICF-MR beneficiaries (as was done with the Medicaid waiver). The current version of the bill (S.873) reflects alternatives offered by the National Association of State Mental Retardation Program Directors and the Association of Retarded Citizens in an attempt to maintain the essential thrust of the original, that is, to secure Medicaid FFP for both

residential and nonresidential community-based services and to reduce federal incentives for the maintenance of large (usually state) institution programs, while defusing some of the major objections to the earlier bill.

A third proposal with major potential impact on the current ICF-MR program was offered by the National Study Group on State Medicaid Strategies (1983), a working group composed of nine state Medicaid public health and human services administrators. This group proposed to split the current Medicaid program into two separate programs. The first would be a federally administered program of medical assistance to needy individuals; the second would be a state-administered program of long-term care, which would include the present ICF-MR program. This second program would be funded in a radically different way than current Medicaid long-term care programs, in that federal support would not be through matching funds but through a direct capitated grant based on, in the case of mentally retarded persons, some index of the number and characteristics of persons needing service. Although identifying the size and nature of each state's target population for computing the size of its grant would be extremely problematic, the Study Group proposal does address the very marked imbalance among states in the amount of Medicaid funding received for residential and related services for mentally retarded people (see Chapter 7).

Several incremental policy options are also under consideration or development. First and foremost on this list is the revision of existing federal standards governing the operation of ICF-MRs. In 1982, as part of the current administration's deregulation initiative, HCFA staff began drafting proposed revision to existing ICF-MR standards, which have been in effect without substantial modification since they were initially issued in January, 1974. The need for revision has generally been acknowledged within the field of mental retardation/developmental disabilities, principally because of the numerous changes that have occurred in the delivery of residential services to mentally

retarded people since the ICF-MR regulations were originally published. HCFA staff have met and worked closely with representatives of a number of professional, provider, and advocacy organizations in the preparation of proposed revisions. The draft regulations, which have undergone two internal revisions, are aimed at correcting currently perceived deficiencies in the ICF-MR standards through the following means:

- * Increasing the regulatory focus on active treatment services by establishing a separate section dealing explicitly with such services;
- * Simplifying existing regulations by eliminating many of the excessively prescriptive requirements (e.g., sections related to the role of discrete professionals in the provision of ICF-MR services);
- * Reducing paperwork and eliminating duplication now present in the 116 separate standards;
- * Increasing the flexibility of ICF-MRs (especially small facilities) to meet the requirements of the standards; and
- * Making the standards—especially those related to active treatment—more enforceable.

Although the proposed regulations are yet to be published, HCFA staff members report that reaction among providers and advocacy groups has generally been supportive of HCFA's efforts. The key issue with the regulations does not appear to be as much one of content, as one of reconciling the desire for greater flexibility under federal standards with the growing evidence of serious compliance problems within state operated facilities, and the generally unknown levels of compliance among private facilities.

Another incremental policy initiative that may assist in the resolution of this issue is HCFA's effort to increase the federal presence in the ICF-MR survey and certification process. As a result of the Senate Subcommittee on the Handicapped hearing on the program described earlier, DHHS Secretary Heckler initiated an expanded series of ICF-MR "look behind" surveys. HCFA has currently hired 43 more survey staff in ten regional offices and added 12 more existing staff from other survey activities to support this effort. The purpose of the federal "look

behind" initiative is to determine whether competent and accountable active treatment is being provided to ICF-MR residents. HCFA plans to survey 100 percent of facilities with 300 or more beds, 40 percent of facilities with 16-299 beds, and 20 percent of all facilities with 15 beds or less. Overall, 650 facilities, representing more than \$3 billion in Medicaid FFP, are to be surveyed.

The impact of federal "look behind" surveys on ICF-MR policy is as yet unclear since the surveys are only beginning. However, there are indications of efforts to rectify some of the previously noted shortcomings of HCFA surveys. The introduction to the new "Protocol for Conducting Direct Federal Surveys of Intermediate Care Facilities for the Mentally Retarded" notes, "Historically, facility surveyors who were not specialists in developmental disabilities, surveyed facilities on a regulation by regulation basis.... Unfortunately, a 'regulation by regulation' way of surveying an ICF-MR does not lead one to an overall decision about the extent to which a facility is providing statutorily mandated active treatment services." In recognition of these past problems new survey teams are expected to include individuals with expertise in developmental disabilities and to carry out specific plan of care reviews, direct observation and interviews with "all levels of staff" involved in the programs of a representative sample of facility residents. These changes could notably improve the usefulness of the survey process in affecting the quality of ICF-MR services. A less visible outcome may be the development of more uniform survey requirements and protocols for assessing the amount and quality of active treatment services provided in ICF-MR facilities. Increased uniformity in federal and state expectations in (1) the assessment of functional, behavioral, and social needs, (2) the design of plans of care and programs with, specified objectives, and (3) the evaluation of the competency of staff providing services, could eventually assist in the resolution of many controversies and ambiguities now surrounding the ICF-MR program.

In addition to these modifications and proposals for the ICF-MR program,

others are made in this report and elsewhere. The interest in the ICF-MR program and the importance attached to "making it work" derives from the fact that it is simply too big and too important to ignore. Clearly its past role has been generally positive, but just as clearly the changing goals for residential services for mentally retarded persons will require the ICF-MR program to change too. This program, or whatever alternative program that might acquire its federal financial and regulatory position, must be willing and able to adapt to the evolving philosophies and knowledge about development, integration, and relative independence of mentally retarded people and the related role of residential programs. The most relevant issue today is not whether the ICF-MR program has been an effective program in the past decade (for the most part it has been), but whether it is or will in the future be able to provide the incentives, the flexibility, and the cost containment necessary for its continued success, while providing equal access of individuals and states to its benefits.

Summary and Recommendations

The passage of Title XIX ended a long history of formal exclusion of mentally retarded people in long-term care settings from federal financial participation (FFP). Prior to the passage of Title XIX in 1965, there had been a thirty year exclusion of institutionalized mentally retarded persons (whether in public or private facilities) from coverage under the Social Security Act. Title XIX continued to exclude retarded persons in public institutions (other than medical institutions) from FFP but allowed otherwise eligible retarded persons in private facilities to qualify.

Title XIX, prior to the 1971 amendment creating ICF-MR had a number of direct and indirect effects on residential care for mentally retarded people. The 1965 Title XIX legislation had three notable effects on the provision of residential care for mentally retarded people. In some states there was a transfer of funding that had been available for the upgrading of all state facilities toward state hospitals for

mentally ill persons, whose sizable populations of elderly residents were made eligible for Title XIX reimbursements if in certified facilities. In about a dozen states, public institutions for retarded persons were being converted to Skilled Nursing Facilities, in which residents could qualify for inpatient coverage under Title XIX. Third, in a few states sizable numbers of public institution residents were transferred to private nursing homes. However, few states exercised the full potential of Title XIX by using the private facility option to expand FFP in providing long-term care for mentally retarded people. In large measure this was because state institutions were perceived as the only viable alternative for providing long-term care for retarded people, and the focus on those facilities was still primarily on their improvement and on the need for increased capacity.

The 1967 amendments to the Social Security Act creating the Intermediate Care Facility (ICF) program continued the prohibition on Title XIX participation of public institutions (unless certified as medical institutions). Advocates for mentally retarded people and state agency personnel hoped that an interpretation of the legislation creating the ICF program would permit the participation of state institutions. However, a 1968 interpretation by Department of Health, Education, and Welfare Secretary Cohen noted that in the legislation Congress "did not modify...[nor] was it their intent to modify the prior exclusions from the assistance programs of 'payments to or care in behalf of an individual who is an inmate of a public institution (except as a patient in a medical institution).'" Similar interpretations were made in 1970 reports of the Senate Committee on Finance and the House Ways and Means Committee.

The major provisions of the ICF-MR program were introduced and passed by the Senate in 1970 amendments to a major welfare reform bill. In 1970 Senate amendments to H.R. 17550 would have authorized ICF program benefits for residents of "a public institution for the mentally retarded or persons with related conditions" if 1) the primary purpose of the institution was to provide health or

rehabilitation services, 2) the mentally retarded persons for whom FFP was requested were receiving "active treatment," and 3) the non-federal expenditures for participating institutions were not replaced by federal payments. However, Senate and House conferees did not reach a compromise on H.R. 17550 before the closing of the 91st Congress.

The ICF-MR program benefit was reintroduced in the 92nd Congress as part of the comprehensive Social Security Amendments Bill, and was one of three provisions selected for expedited consideration (and passage). The ICF benefit for residents of public institutions for mentally retarded people was reintroduced in the 92nd Congress as part of amended language on Intermediate Care contained in the Social Security Amendments Bill (H.R. 1). Consideration of ICF language was one of three provisions of H.R. 1 that was given expedited consideration in that session. This language, which was appended to another bill, received no debate, merely explanation by its supporters, and was quickly moved through both houses and through Conference. A final bill was passed on December 14, 1971. There are no indications in the public record of any concerns at the time about the size and/or costs of the new ICF benefit for residents of public institutions for mentally retarded people.

In creating the ICF-MR benefit, Congress intended to create a fiscal incentive to upgrade the quality of environment, care, and habilitation in public institutions. A major objective of Congress in approving a benefit for retarded persons in public institutions was to provide states with an incentive to upgrade the quality of care provided in public institutions. Unlike the ICF-general, the ICF-MR program was not conceptualized as a means to cost savings, but instead as a means to expand Medicaid coverage to a specific population whose general quality of care was an increasingly well publicized national scandal. The ICF-MR program represented a national commitment to assist individual states in improving these facilities. This commitment was reflected both in the nature of standards established for the

program and also in the initial stipulation that federal funds provided would augment, not supplant, state funds being spent prior to the certification of these facilities as ICF-MR providers. In other words, there was a general expectation, one that was only partially realized (see Chapter 7) and no longer required after 1975, that the funds available through the ICF-MR program would be used to offset the increased costs of providing better care.

Creation of the ICF-MR program responded to serious concerns among advocates for mentally retarded people and federal investigators that previous Title XIX and Title XI (SNF and ICF) provisions, in the absence of legislation specifically targeted on public institutions for retarded people, was having a negative effect on the quality of care. A major stimulus to consideration of the ICF-MR legislation was the increasing effort of states to utilize the existing authority for SNF and ICF care to increase FFP for the care of retarded persons by certifying their public institutions as Skilled Nursing Facilities or by transferring their mentally retarded residents to private SNF or ICF nursing homes. Intra-government audits, numerous advocacy groups, and many state and institution administrative leaders argued the standards of the programs were inappropriate for services to mentally retarded persons. The creation of the ICF-MR program in Public Law 92-223 attempted to neutralize incentives for ICF and SNF placements by providing equal FFP for retarded persons in programs generally considered more appropriate.

The creation of the ICF-MR program authorized a program directly focused on the frequently unmet, specialized needs of mentally retarded people. Congress did not intend with this program merely to provide a "cleaner" funding mechanism to support the costs of non-nursing home residential care for mentally retarded people. Section 1905 specifically stipulates that the provision of "active treatment" is a primary criterion for obtaining FFP with the costs of the residential and habilitative programs within the public institutions. Although the term was not well-defined in statute or in committee reports, it was clear that participating

facilities were expected to offer programs that included a major emphasis on training and habilitation. Congressional recognition that the needs of mentally retarded persons often differ significantly from those of disabled elderly participants in other Medicaid long-term care programs is clear in the statutory language, which stipulated that ICF-MRs need not focus primarily on health care (as was the case for general ICFs), but on health or rehabilitative service.

The ICF-MR program was developed to stimulate improved care and habilitation in large public institutions, but by employing the generic federal definition of "institution," the one also used for ICF-general program, public and private facilities of four or more beds were made eligible to participate. The federal definition of "institution" which serves as the basis for facility participation in the ICF-MR program defines institutions as "facilities serving four or more persons in single or multiple units." The origination of this definition came from the recognition that many of the facilities that would be able to provide elderly and disabled persons with intermediate care were small. This encompassing definition of institution, which became that of the ICF-MR program by virtue of its being an offshoot of the ICF-general program, permitted the development and growth of the small and private facilities participating in the ICF-MR. The ability of states to obtain reimbursement for ICF-MR levels of care outside of state institutions was a major impetus to the deinstitutionalization movement.

Eventual ICF-MR regulations and the subsequent deadlines for complying with them represent a compromise between the position of states, arguing for minimum specific standards and maximum periods for compliance, and advocacy groups, arguing for stringent standards and compliance before receiving FFP. Because the eventual federal regulations for participation were relatively demanding, although less so than the Accreditation Council for Facilities for the Mentally Retarded/Developmentally Disabled on which they were modeled, states were permitted to meet a minimum set of standards for original participation with the

requirement that full compliance be attained by March 1977. This initial opportunity for program participation without compliance with the established standards was followed by a number of other delays in requirements for compliance (through 1982) that have become among the most controversial aspects of the program. While there is no way to demonstrate that delays in compliance requirements slowed down what otherwise would have been more concerted state efforts to improve their institutions (perhaps in the absence of these delays states, deprived of FFP, would have been unable or unwilling to upgrade their institutions) it is hard to argue in retrospect that compliance deadline delays proved to be a successful departure from the logical assumption that the sooner states faced the loss of FFP the quicker they would respond.

In addition to demanding a quality of care substantially above that available in most state institutions, the ICF-MR regulations were indirectly responsible for substantial institutional depopulation. The ICF-MR regulations for sleeping rooms, which were based on existing standards for Skilled Nursing Facilities, permitted not more than four beds per room and not less than 60 square feet per bed. In many institutions these standards not only required significant amounts of facility renovation, but simply could not be met without substantial reductions in their total resident populations. On the other hand, institutions were frequently allowed variances from the sleeping room standards on the permissible grounds that assignment to sleeping rooms or wards with more than 4 persons was somehow "in accordance with [the individual's] program needs."

The ICF-MR regulations, issued in January 1974, made clear the possibility and conditions for providing ICF-MR care in facilities of 15 or fewer residents. The 1974 standards issued by HCFA to regulate the ICF-MR program made clear not only that the ICF-MR level of care could be delivered in small facilities, but that considerable flexibility was permissible with respect to the delivery of the professional services required of ICF-MR providers. Unfortunately, HCFA

Regional Offices were not always supportive of states' desire to utilize this alternative for potential beneficiaries, which quite probably delayed the community reentry of many hundred mentally retarded persons in need of an ICF-MR level of care. To clarify a national policy of the small ICF-MR program HCFA issued interpretative guidelines in 1981, followed by substantial growth in the numbers of small ICF-MR facilities and the number of states developing them.

Monitoring procedures established for assuring the compliance of long-term care vendors under Medicaid have not been effective in assuring the ICF-MR compliance of state institutions. Recent reports and hearings of the Senate Subcommittee on the Handicapped and testimony of the Secretary of the Department of Health and Human Services (as a party to a consolidated suit brought in response to care in ICF-MR certified state institutions in Massachusetts) have brought considerable attention to the substandard care provided in certain state institutions, whose own state survey agencies have certified as complying with ICF-MR standards. Concern about the appropriateness of having a state government monitor its own compliance when millions of dollars of FFP to its own coffers lies in the balance is not new, but the recent publicity has resurrected it. It may be anticipated that because of this attention HCFA will be compelled to substantially increase its staffing and the use of the "look behind" authority that was vested in its regional offices in 1980, compelled to implement policy requiring that an independent, non-state government agency be employed to survey state-operated programs and approve and monitor plans of correction, or compelled to undertake some other modification of current practice. If such policy changes are not required from outside HCFA, they should be pursued internally.

Too little is known about the compliance to ICF-MR standards in small, private residential facilities. While states have no obvious vested interest in not carrying out their responsibility to monitor whether the prescribed ICF-MR level and components of care are delivered to residents of small, private facilities, no

external evaluation has documented compliance of such facilities or the appropriateness of completeness of state surveys. Such studies would be more difficult than similar surveys in state institutions, given that the expectations for such facilities have been provided as general guidelines rather than objective standards. Nevertheless, analyses of the extent to which the care provided generally reflects the ICF-MR level is badly needed. Designing and carrying out such research must obviously involve persons able to translate ICF-MR institutional standards and small facility guidelines into objective indicators of the nature and intensity of care being provided.